DHEW HEALTH RESEARCH PRINCIPLES

Volume I

Documents Relating to the

Development of

Draft Health Research Principles

for the

Department of Health, Education, and Welfare

April - December 1978

Appendices A and B

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Documents Relating to the
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APPENDIX A



INTRODUCTION

In July, approximately 1,000 professional societies and health organizations were asked for their views and suggestions on health research principles for the Department and subsequently invited to participate in the National Conference. This appendix lists the professional societies and health organizations that were sent the July 19 memorandum from the Secretary, DHEW and the August 11 memorandum from the Director, NIH. (Copies of these memoranda are reproduced in Volume I.) This list is organized in alphabetical order and was compiled from lists submitted by the DHEW agencies and staff offices participating in the Secretary's planning initiative.



AAAS PROJECT ON THE

HANDICAPPED IN SCIENCE

1776 MASSACHUSETTS AVE NW

WASHINGTON DC

ACADEMY OF GENERAL DENTISTRY

211 E CHICAGO AVE

CHICAGO IL

60611

ACADEMY OF PHARMACEUTICAL SCIENCES 2215 CONSTITUTION AVE NW WASHINGTON DC 20037

ACADEMY OF PHARMACY PRACTICE 2215 CONSTITUTION AVE NW WASHINGTON DC

20037

ACADEMY OF PHYSICIAN ASSISTANTS
2341 JEFFERSON DAVIS HGWY
ARLINGTON VA 22202

ACADEMY OF PSYCHOSOMATIC MEDICINE EOX 1053 MOUNTAINSIDE NJ 07092

ACADEMY OF VETERINARY ALLERGY
322 FRONTAGE RD

KENNETH S STEVENS PH D
ACOUSTICAL SOCIETY AMER NORTHFIELD IL

RESEARCH LAB OF ELECTRONICS MA INSTITUTE OF ELECTRONICS

60093 CAMBRIDGE MA 02139

MR PATRICK J CARRY ADA MCCONNELL CLARK FOUNDATION

ROOM 900

342 MADISON AVE 250 PARK AVE NEW YORK NY 10017

NEW YORK NY

10017

AGPICULTURAL RESEARCH 2100 PA AVE NW WASHINGTON DC 20037

AGRICULTURE COUNCIL OF AMER SUITE 1025 1625 EYE ST NW
WASHINGTON DC 20006

AIR POLLUTION CONTROL ASSN ALAN GUTTMACHER INSTITUTE 4000 FIFTH AVE PITTSBURGH PA 15213

515 MADISON AVE NEW YORK NY 10022

MR AUGUSTUS HEWLETT

ALCOHOL AND DRUG PROBLEMS ASSN
OF NORTH AMER

ACCOMPAND OF NORTH AMER

ACCOMPAND OF NORTH AMER

ACCOMPAND OF NORTH AMER

BOX 251 OF NORTH AMER

1101 15TH ST NW

WASHINGTON DC

20005

GENERAL SERVICE EOARD

BOX 251

NEW LONDON NH

03257

ALEXANDER GPAHAM BELL ASSN
FOR THE DEAF INC
3417 VOLTA PLACE NW

MR HARRY E WILSON
ALLERGY FOUNDATION
801 SECOND AVE 3417 VOLTA PLACE NW WASHINGTON DC 20007

ALLERGY FOUNDATION OF AMER NEW YORK NY 10017

ALLIANCE FOF ENGINEERING MEDICINE AND BIOLOGY 4405 EAST-WEST HIGHWAY BETHESDA, MD	IN 20014	ALLIANCE FOR ENG MEDICINE AND BIO 5454 WISCONSIN A CHEVY CHASE MD	INEERING LOGY VE #1350	IN 20015
MR R V PEGRAM ALS FOUNDATION INC 2840 ADAMS AVE SAN DIEGO CA	92116	MR H EAMES BISHO ALS SOCIETY OF A SUITE #350 15300 VENTURA BO SHERMAN OAKS CA	F MER ULEVARD	91403
ALTERNATIVES TO ABORTION HILCREST HOTEL SUITE 511 16TH AND MADISON ST TOLEDO OH	46624	DR CHARLES D SHE AMA ADVISORY COM CANCER 260 CRITTENDEN B ROCHESTER NY	RMAN MITTEE ON CULEVARD	14642
AMBULATORY PEDIATRIC ASSI COLLEGE OF MEDICINE UNIVERSITY OF ARIZONA TUCSON AZ	N 85724	MR ROGER TUSKEN AMER ACAD OF PAM EXECUTIVE DIRECT 1740 W.92ND STRE KANSAS CITY, MIS	ILY PHYSI CR EFT SOURI	CIANS 64114
MR JAMES E BRYAN AMER ACADEMY FOR CEREBRAI PALSY. 1255 NH AVE NW WASHINGTON DC				
DR TOM VAN METRE JR AMER ACADEMY OF ALLERGY 11 E CHASE ST BALTIMORE MD	21202	MRS VIRGINIA Q E AMER ACADEMY OF PSYCHIATRY 1800 R ST NW #90 WASHINGTON DC	BAUSCH CHILD	20009
DRESTORNT		AMER ACADEMY OF RADIOLOGY MEDICAL COLLEGE AUGUSTA GA	CENTAL	30902
MR BRADFORD CLAXTON AMER ACADEMY OF DERMATOLO 820 DAVIS ST EVANSTON IL	OGY 60201	AMER ACADEMY OF ENGINEERS PO BOX 1278 ROCKVILLE MD	ENVIRONME	20850
MR ROGER TUSKEN AMER ACADEMY OF FAMILY PHYSICIANS 1740 W 92ND ST KANSAS CITY MO	64 11 4	AMER ACADEMY OF SCIENCES 11400 ROCKVILLE ROCKVILLE MD		20852

20006 WASHINGTON DC

C M KOS MD AMER ACADEMY OF OPHTHALMOLOGY
AND OTOLARYNGOLOGY
15 SECOND ST SW 15 SECOND ST SW ROCHESTER MN 55901

DR CHARLES V HECK

AMER ACADEMY OF ORTHOPEDIC

AMER ACADEMY OF PEDIATRICS

1801 HINMAN AVE 60611 CHICAGO IL

DR MARVIN E WOLFGANG 3937 CHESTNUT ST PHILADELPHIA PA 19104

AMER AND INTERNATIONAL ASSN
FOR DENTAL RESEARCH
734 15TH ST NW #809
WASHINGTON DC

20005

DR EDWARD J LEHMAN
AMER ANTHROPOLOGICAL ASSN
1703 NEW HAMPSHIRE AVE NW
WASHINGTON DC

DP HUGH J CREECH .

MR KEN BALLARD

AMER ASSN FOR COMPREHENSIVE
HEALTH PLANNING
801 N FAIRFAX ST SUITE 212
ALEXANDRIA VA
22314

MR J J GARVEY
AMER ASSN FOR LAEORATORY
ANIMAL SCIENCE
2317 W JEFFERSON ST #208
JOLIET IL

AMER ACADEMY OF MICROBIOLOGY

AMER ACADEMY OF NEUROLOGICAL

1913 EYE ST NW SURGERY
710 W 168TH ST
NEW YORK NY 10032

MR STANLEY A NELSON

AMER ACADEMY OF NEUROLOGY

4015 W 65TH ST

MINNEAPOLIS MN

55435

CP DONNA AGUILERA

AMER ACADEMY OF NURSING

C/O AMER NURSES ASSN

2420 PERSHING RD

KANSAS CITY MO

64108

FREDERICK BLODI MD AMER ACADEMY OF OPHTHALMOLOGY IOWA STATE UNIVERSITY IOWA CITY IA 52242

60204

J SANDERS PIKE DDS

AMER ACADEMY OF PEDODONTICS

3126 PIEDMONT RD NE

ATLANTA GA

30305

DR CRESTON C HERCLD

AMER ACADEMY OF PHYSICAL

MEDICINE AND REHABILITATION

30 N MICHIGAN AVE SUITE 922

CHICAGO IL

606

DR JOHN SCHIMEL AMER ACADEMY OF POLITICAL AND
SOCIAL SCIENCE

AMER ACADEMY OF PSYCHOANALYSIS
40 GRAMERCY PARK NORTH NEW YORK NY

10010

20009

DP HUGH J CREECH GUSTAVE BECK MD

AMER ASSN FOR CANCER RESEARCH AMER ASSN FOR CLINICAL

7701 BURHOLME AVE
PHILADELPHIA PA

19111 NEW YORK NY GUSTAVE BECK MD 10021

AMER ASSN FOR MATERNAL AND

CHILD HEALTH INC

116 SOUTH MICHIGAN AVE

CHICAGO IL

60603

AMER ASSN FOR MATERNAL/CHILD

HEALTH

FO BOX 965

LOS ALTOS CA

94022 AMER ASSN FOR FFHABILITATION AMER ASSN FOR RESPIRATORY THERAPY THERAPY PO BOX 93

NORTH LITTLE ROCK AK 72116

DALLAS TX 75235 MP WILLIAM CAREY

AMER ASSN FOR THE ADVANCEMENT

OF SCIENCE

1776 MASSACHUSETTS AVE NW
WASHINGTON DC

SEYMOUR DIAMOND MD

AMER ASSN FOF THE STUDY OF

HEADACHE

5252 NORTHWESTERN AVE

CHICAGO IL

606 60625 POPERT ZEPPA MD

AMER ASSN FOR THE STUDY OF

LIVER DISEASES

PO BOX 520875

AMER ASSN FOR THORACIC SURGERY

SIX BEACON ST #620

BOSTON MA POPERT ZEPPA MD 33 152 02108 MIAMI FL DR ASAO HIPANO AMER ASSN OF NEUROPATHOLOGISTS DR JOHN E PAULY AMER ASSN OF ANATOMISTS
NEUROPATHOLOGISTS
MONTEFIORE HOSPITAL
BRONX, NY

AMER ASSN OF ANATOMISTS
DEPARTMENT OF ANATOMY
UNIVERSITY OF AK MEDICAL CNTR
LITTLE ROCK AK
72201 72201 DR HOWARD F TASHWELL

AMER ASSN OF BIOANALYSTS
SHITE 805
411 N SEVENTH ST
5T LOUIS MO 63101

DR HOWARD F TASHWELL

AMER ASSN OF BLOCD BANKS
SUITE 608
1828 L ST NW
ST LOUIS MO 63101

WASHINGON DC 20036

DR PETER WHYBROW

AMER ASSN OF CEREAL CHEMISTS

AMER ASSN OF CHAIRMEN OF

3340 PILOT KNOB RD

DEPARTMENTS OF PSYCHIATRY

DARTMOUTH MEDICAL SCHOOL

55121

HANOVER NH

30755

WASHINGTON DC 20036

DE CHRISTOPHER A RODOWSKAS JR

AMER ASSN OF COLLEGES OF
PHARMACY
FODIATRIC MELICINE
4640 MONTGOMERY AVE #201
BETHESDA MD
20014
WASHINGTON DC
20015

DR MARY KELLY MULLANE

AMER ASSN OF COLLEGES OF

NURSING

11 DUPONT CIPCLE NW

CR ANTHONY J MC NEVIN

AMER ASSN OF COLLEGES OF

OSTEOPATHIC MEDICINE

4720 MONTGOMERY LA #609 BETHESDA MD 20014

ARNOLD M KALLEN MD

AMER ASSN OF COMMUNITY CLINIC

AND CENTER PSYCHIATRISTS

PO BOX 70

LIVINGSTON NJ

O7039

ORANGE CA

92667

10017

JACK H PETAJAN MD AMER ASSN OF ELECTROMYOGRAPHY
AND BLECTRODIAGNOSIS
COLLEGE OF MEDICINE U OF U
SALT LAKE CITY UT
84112

MER ASSN OF FEEL
MICROSCOPISTS
PO BOX 586
SQUINCY IL
62301

DR DAVID W TALMAGE AMER ASSN OF IMMUNOLOGISTS

WEBB-WARING INSTITUTE

ASSN OF INDIAN
PHYSICIANS INC
ASSN OF INDIAN
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1300 MCGEE DR ### 103
DENVER CO

80220

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AMER ASSN OF LABORATORY

ANIMAL SCIENCES

2317 W JEFFERSON ST

JOLIET IL

60435

AMER ASSN OF MEDICAL

ASSISTANTS
ONE E WACKER DR
CHICAGO IL

GABRIELE ZURHEIN MD

AMER ASSN OF NEUROPATHOLOGISTS
MEDICAL SCHOOL U OF WISC

470 N CHARTER ST
NADISON WI

53706

MR. LAWRENCE A. ZUPAN

AMER ASSN OF OPHTHALMOLOGY

EXECUTIVE SECRETARY

1100 17TH STREET N.W.

WASHINGTON, DC

200

MRS BETTY BLUMBERG

AMER ASSN OF DENTAL EDITORS

AMER ASSN OF DENTAL EXAMINERS

30 EAST 42ND ST #1606

NEW YORK NY

AURORA II.

60506

DR HARRY BRUCE

AMER ASSN OF DENTAL SCHOOLS

1625 MASS AVE NW #300

WASHINGTON DC

20036

DR GARY TUCKER

AMER ASSN OF DIRECTORS OF

PSYCHIATRIC RESIDENCY TRAINING

UNIV OF DARTMOUTH MEDICAL COLL

HANOVER NH

03755

73069

MR DAVID CROWLEY MR DAVID CROWLEY

AMER ASSN OF FOUNDATIONS FOR

MEDICAL CARE

1900 M ST NW #730

WASHINGTON DC

MR DAVID CROWLEY

AMER ASSN OF HOMES FOR THE

AGING

1050 17TH ST NW

WASHINGTON DC

20036

1300 MCGEE DR #103

ONE E WACKER DR CHICAGO IL 60601

AMER ASSN OF MEDICO-LEGAL
CONSULTANTS
2200 BENJAMIN FFANKLIN PKY
PHILADELPHIA PA
19130

LESTER MOUNT MD
AMER ASSN OF NEUROLOGICAL
SURGEONS
710 W 168TH ST
NEW YORK NY
10032

AMER ASSN OF PASTORAL
COUNSELORS
AND BACTERIOLOGISTS
3 WEST 29TH ST
NEW YORK NY
10001
ALBUQUERQUE NM
87131 MP KENNETH PEPPER

DP SHARON PIERCE AMER ASSN OF PHYSICISTS IN

MEDICINE

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CHICAGO IL

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69 BUTLER ST

ATLANTA GA

30303

W O FOBERTSON MD AMER ASSN OF POISON CONTROL
CENTERS
PO BOX C5371
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98105

AMER ASSN OF PSRCS
FO BOX 230
STOCKTON CA

MS DEBORA KRAMER

AMPR ASSN OF PSYCHIATRIC

SEPVICES FOR CHILDREN

1725 K ST NW #1112

WASHINGTON DC

DR KENNETH R ELWELL

AMER ASSN OF PUBLIC HEALTH

DENTISTS

2123 ABINGTON RD

CLEVELAND OH

44106 44106

AMER ASSN OF PUBLIC HEALTH

PHYSICIANS
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1703 RIDGEMONT

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78723

AMER ASSN OF SEX EDUCATORS
AND COUNSELORS
5010 WISCONSIN A VE NW
WASHINGTON DC

20016

MR S D LOVEJOY

AMER ASSN OF SMALL RESEARCH

COMPANIES

1629 K ST NW #5013

WASHINGTON DC

MS CHRISTINA BITTING

AMER ASSN OF STATE COLLEGES

AND UNIVERSITIES

CNE DUPONT CIRCLE NW #700

WASHINGTON DC

20036

R R BELL DVM

AMER ASSN OF VETERINARY

LAPORATORY DIAGNOSTICIANS

5101 MINERAL POINT RD

MADISON WI

53705

R R BELL DVM

AMER ASSN OF VETERINARY

FARASITOLOGISTS

TEXAS A&M UNIVERSITY

COLLEGE STATION TX

MS JOSEPHINE RATHIE

AMER ASSN OF VOLUNTEER SERVICE
COORDINATORS
18 S MICHIGAN AVE
CHICAGO IL

MR. BRUCE FLASCH
AMER ASSN OF WORKERS
FOR THE BLIND, INC.
1511 K STREET, N. W.
WASHINGTON, DC

DP BERKOWITZ AMER ASSN ON MENTAL DEFICIENCY

5101 WISCONSIN AVE NW

WASHINGTON DC

20016

AMER ASSOCIATION FOR

MATERNAL AND CHILD HEALTH

P O BOX 965

LOS ALTOS, CA

94022

AMER ASSOCIATION OF AMER ASSOCIATION OF FEED MICROSCOPISTS
P O BOX 586 CRITICAL CARE NURSES 2192 MARTIN
ORANGE, CA
92667
QUINCY, ILLINOIS
62301 DR JOHN BERNARD EENRY AMER BAR ASSN AMER BLOOD COMMISSION 1800 M ST NW SUITE 300 1901 NORTH FT MY FR DR WASHINGTON DC 20036 ARLINGTON VA CLARENCE LIVINGOCD MD
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65 CERAMIC DR COLUMBUS OH CINNAMINSON NJ 08077 43214 AMER CHIROPRACTIC ASSN
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50312 AMER COLL OF GNRI PRACTITIONER IN OSTEOPATHIC MED & SURGERY 111 W WASHINGTON ST #17 CHICAGO IL 60602 MR JAMES W DILLEY AMER COLLEGE HEALTH ASSN

AMER COLLEGE OF

ANESTHESIOLOGISTS

EVANSTON IL

60201

AMER COLLEGE OF

ANESTHESIOLOGISTS

515 BUSSE HIGHWAY

PARK RIDGE IL 60068 WILLIAM S ROSENTHAL MD AMER COLLEGE OF
GASTROENTEROLOGY
299 BROADWAY
NEW YORK NY
10007
AMER COLLEGE OF
NEUROPSYCHOPHARMACOLOGY
591 MORTON ST
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02124 AMER COLLEGE OF DR ALBERT E HENSEL JR

AMER COLLEGE OF ALLERGISTS

1270 SOUTHAMPTON DR

ALEXANDRIA LA

MP WILLIAM D NELLIGAN

AMER COLLEGE OF CARDIOLOGY

9111 OLD GEORGET CWN RD

BETHESDA MD 71301

911 BUSSE HIGHWAY PARK RIDGE IL 60068

A MER COLLEGE OF LABORATORY
A NIMAL MEDICINE
MEDICAL SCHOOL UNIV OF MA
WORCESTER MA
O1605

AMER COLLEGE OF LEGAL MEDICINE
1340 ASTOR ST #1201
CHICAGO IL
60610

MS FAY LEBOWITZ

AMER COLLEGE OF NURSE-MIDWIVES

1000 VERMONT AVE NW #500

WARREN PIERCE MD

AMER COLLEGE OF CB GYN

CNE EAST WACKER DR

CHICAGO IL

20005

PHILADELPHIA PA 19136 MERRILL MI

EDWARD C ROSENOW JR MD

AMER COLLEGE OF OSTEOPATHIC

PETIATRICIANS

PO BOX 340488

COPAL GABLES FL

EDWARD C ROSENOW JR MD

AMER COLLEGE OF PHYSICIANS

4200 PINE ST

PHILADELPHIA PA

191 COPAL GABLES FL 33134

19010 801 OLD LANCASTER RD BRYN MAWR PA

NOFMAN Q BRILL MD AMER COLLEGE OF PSYCHOANALYSTS
AMER COLLEGE OF RADIOLOGY
760 WESTWOOD PLAZA
LOS ANGELES CA

90024

AMER COLLEGE OF RADIOLOGY
CHICAGO IL
60

DR C ROLLINS HANLON 55 E ERIE CHICAGO IL 60611 AMES IA

ALFRED SOFFER MD

AMER COLLEGE OF CHEST
PHYSICIANS

211 RUSSE HIGHWAY

MR ROBERT J NELSEN

AMER COLLEGE OF CENTISTS

7316 WISCONSIN AVE #304

BETHESDA MD BETHESDA MD

20014

PRESIDENT AMER COLLEGE OF EMERGENCY

PHYSICIANS

3900 CAPITOL CITY BLVD

EAST LANSING MI

AMER COLLEGE OF HOSPITAL

ADMINISTRATORS

840 N LAKE SHORE DR

CHICAGO IL

6

60611

60601

AMER COLLEGE OF OSTEOPATHIC
INTERNISTS
OBSTETRICIANS AND GYNECOLOGIST
BOX 66

19104

JOHN C NEMIAH MD

AMER COLLEGE OF PREVENTIVE
MEDICINE
330 BROOKLINE AVE
BOTON MA 02215

60606

AMER COLLEGE OF SURGEONS
AMER COLLEGE OF VETERINARY
55 E ERIE PATHOLOGISTS FATHOLOGISTS
NADL BOX 70
55010

AMER CONGRESS OF REHABILITATION MEDICINE
30 N MICHIGAN AVE AMER COUNCIL FOR THE BLIND INC 1211 CONNECTICUT AVE, N.W. 30 N MICHIGAN AVE
CHICAGO IL

60602

SUITE 506
WASHINGTON, EC 20036 HARRY MC CURDY MD MR. FLOYD QUALLS AMER COUNCIL OF THE BLIND, INC AMER COUNCIL OF OTOLARYNGOLOGY 1100- 17TH ST NW #602 PRESIDENT WASHINGTON DC 329 WOODBURY LANE 20036 TOPEKA, KANSAS 66606 MR JACK W PELTASON
AMER COUNCIL ON EDUCATION MR JACK W PELTASON AMER COUNCIL ON PHARMACEUTICAL EDUCATION ONE E WACKER DR WASHINGTON DC 20036 CHICAGO IL 60601 MS JOAN SMALLWOOL AMER DANCE THERAPY ASSN AMER DAIRY ASSN 6300 N RIVER RD 2000 CENTURY PLAZA #210 ROSEMONT IL COLUMBIA MD 60018 21044 MR CARL H HAUBER MS LOIS KLINGER AMER DENTAL ASSISTANTS ASSN 211 EAST CHICAGO AVE #1230 AMER DENTAL HYGIENISTS ASSN 211 EAST CHICAGO AVE #1616 CHICAGO IL CHICAGO IL 60611 60611 MR EDMUND WELLINGTON JR ANTHONY N DOMONKOS MD AMER DERMATOLOGICAL ASSN AMER DENTAL TRADE ASSN 1140 CONNECTICUT AVE NW 115 E 61ST ST WASHINGTON DC NEW YORK NY 20036 10021 DR JOHN L DUGAN JR MS CLARA ZEMPEL AMER DIABETES ASSN AMER DIETETIC ASSN 600 5TH AVE 430 NORTH MICHIGAN AVE CHICAGO IL NEW YORK NY 10020 60611 HENRY COLCHER MD AMER DIGESTIVE AMER DYE MANUFACTURERS INST DISEASES SOCIETY ONE E 57TH ST 420 LEXINGTON AVE #1712 NEW YORK NY

NEW YORK NY

AMER EGG BOARD

205 TOUHY AVE

PARK RIDGE IL

10017

10022

MRS MARGARET H HENRY AMER ELECTROFNCEPHALOGRAPHIC SOCIETY 4137 ERIC ST 60068 WILLOUGHBY OH 44094 AMER ENTERPRISE INSTITUTE FOR

PUBLIC POLICY

1150 17TH ST NW *1200

WASHINGTON DC

DAVID D DALY MD

AMER EPILEPSY SOCIETY

DEPARTMENT OF NEUROLOGY

5323 HARRY HINES BLVD

DALLAS TX

DR GERALD F DI BONA

AMER FEDERATION FOR

CLINICAL RESEARCH

COLLEGE OF MEDICINE U OF IA

IOWA CITY IA

MR KENNETH BLAYLCCK

AMER FEDERATION CF

GOVERNMENT EMPLOYEES

1325 MASSACHUSETIS AVE NW

WASHINGTON DC

20005

AMER FEDERATION OF STATE

COUNTY AND MUNICIPAL EMPLOYEES

1701 N FT MYER DR

ARLINGTON VA WASHINGTON DC 20036

AMER FERTILITY SOCIETY
SUITE 101 1608 13TH AVE S BIRMINGHAM AL 35205

MR L E APPLE AMER FOUNDATION FOR THE ELIND

AMER FROZEN FOOD INSTITUTE

15 W 16TH ST

NRW VORK NV

WASHINGTON DC NEW YORK NY 10011

60611

NEW YORK NY

DR HENRIETTE GLATZER

AMER GROUP PSYCHOTHERAPY
ASSN INCORPORATED
1995 BROADWAY
NEW YORK NY
10023

EXECUTIVE VICE PRESIDENT
AMER HEALTH CARE ASSN
1200 15TH ST NW
WASHINGTON DC
20005

75235

MR LEO PERLIS AMER FARM BUREAU

RESEARCH FOUNDATION

225 TOUHY AVE

PARK RIDGE IL

AMER FED OF LABOR & CONGRESS
OF INDUSTRIAL ORGANIZATIONS
815 16TH ST NW
WASHINGTON DC

2000

22209

AMER FORESTRY ASSN 1319 18TH ST NW WASHINGTON DC

20036

WASHINGTON DC

20006

MR ROBERT J DESMOND

AMER FUND FOR DENTAL HEALTH

211 EAST CHICAGO AVE #1630

CHICAGO IL

JOHN A BENSON MD

AMER GASTROENTEROLOGICAL ASSN
6900 GROVE RD
THOROFARE NJ

08086

KATHRYN 3 HENDERSON

AMER GERIATRICS SOCIETY

10 COLUMBUS CIRCLE #1470

NEW YORK NY

EXECUTIVE DIRECTCR

AMEF GROUP PRACTICE ASSN
FO BOX 949
20 SOUTH QUAKER LANE 10019 ALEXANDRIA VA 22313

DR ERNST L WYNDER
AMER HEALTH FOUNDATION
1370 AVE OF THE AMER AMER HEALTH PLANNING ASSN 2560 HUNTINGTON AVENUE NEW YORK NY SUITE 305 ALEXANDRIA, VA 22303 10019 MR WILLIAM W MOORE AMER HEART ASSN MR RUSSELL R WILHERTON AMER HEPATIC FOUNDATION 7320 GREENVILLE AVE SMITHWICK PO BOX 1005 DALLAS TX 75231 WILLIAMSTON NC 27892 DR JOHN H BUDD AMER HOSPITAL ASSN MR MILTON SEARLE AMER HUMANE ASSN 5351 SOUTH ROSLYN ST 840 N LAKE SHORE DR INGLEWOOD CO CHICAGO IL 60611 80110 MS JANICE KEKEHBAH AMER INDIAN NURSES ASSN AMER INDIANS 321 SOUTH PETERS ST 4401 MONTGOMERY EOULEVARD NE NOFMAN OK NO 118 ALBUQUERQUE NM 87109 73069 AMER INDUSTRIAL HYGIENE ASSN
AMER INST OF BIOLOGICAL SCI
AVEN OH

AKRON OH 44311 ARLINGTON, VA 22209 DR RICHARD TRUMBULL
AMER INSTITUTE OF BIOLOGICAL
SCIENCES AMER INSTITUTE OF BAKING 400 E ONTARIO ST CHICAGO IL 1401 WILSON EOULEVARD 60611 ARLINGTON VA 22209 DR HAMISH MUNRO
AMER INSTITUTE OF NUTRITION
9650 ROCKVILLE PIKE AMER INSTITUTE OF MINING METAL AND PETROLEUM ENGG. BETHESDA MD 345 E 47TH ST NEW YORK NY 10017 20014 AMER INSTITUTE OF PHYSICS

AMER INSTITUTE OF ULTRASOUND
IN MEDICINE NEW YORK NY PO BOX 26901 10017 OKLAHOMA CITY OK 73190 PRESIDENT AMER INSURANCE ASSN MS. SARAH EHRMAN AMER JEWISH CONGRESS 85 JOHN ST NEW YORK NY 1522 K STREET, N. W.
10038 WASHINGTON, DC 20005 AMFR KIDNEY FUND
7315 WISCONSIN AVE BETHESDA MD

20014

46206

RICHARD L RUGGLES MD AMER LARYNGOLOGICAL RHINOLOGICAL AND OTOLOGICAL 11201 SHAKER BOULEVARD 44104 CLEVELAND OH

MR WILLIAM F HANCK 700 N PENNSYLVANIA ST INDIANAPOLIS IN MR ROGER K ACKLEY AMER LEPROSY MISSIONS 1260 BROAD ST BLOOMFIELD NJ

07003

BURTON COMBES MD

AMER LIVER POUNDATION
UNIVERSITY OF TEXAS
5323 HARRY HINES BOULEVAPD
DALLAS TX

75235

ETHELENE CROCK
AMER LUNG ASSN
1740 BROADWAY
NEW YORK NY

ETHELENE CROCKETT AMER LUNG ASSN 1740 BROADWAY

10019

AMER MATHEMATICAL SOCIETY
PO BOX 6248 PROVIDENCE RI 02940

AMER MEAT INSTITUTE PO BOX 3556 WASHINGTON DC

20007

AMER MEAT INSTITUTE FOUNDATION
1600 N WILSON BOULEVARD 1600 N WILSON BOULEVARD ARLINGTON VA

22209

ROBERT JEUB MD AMER MEDICAL ELECTROENCEPHALOGRAPHIC ASSN 825 NICOLLER ON THE MALL #1747 MINNEAPOLIS MN

DR JAMES H SAMMONS AMER MEDICAL ASSN 535 N DEARBORN ST CHICAGO IL

JOSEPH J ZUSKA MI AMER MEDICAL SOCIETY ON ALCOHOLISM INC 733 3RD AVE
60610 NEW YORK NY 10017

MR PAUL WRIGHT

AMER MEDICAL STUDENT ASSN
PO BOX 131
ASSN
14650 LEE RD
CHANJILLY VA
22021
AMER MEDICAL TECHNOLOGISTS
ASSN
710 HIGGINS AVE
60068

AME! MEDICAL WOMEN'S ASSN 1740 BROADWAY NEW YORK NY

MS SHERYLL SUE CARELLA AMER NARCOLEFSY ASSN

10019

524 SKIFF CIRCLE
REDWOOD CITY, CA 94065

MR BILL BAIRD AMER NARCOLEPSY ASSN
PO BOX 5846 STANFORD CA

MR GEORGE M FLSEY AMER NATIONAL RED CROSS WASHINGTON DC 17TH AND E SI NW

94305

AMER NATIONAL STANDARDS AMER NATL CATTLEMEN'S ASSN 1001 LINCOLN ST INSTITUTE 1430 BROADWAY 10018 DENVER CO 80203 FRED PLUM MD ERIAN F MCCAEE MI AMFR NEUROLOGICAL ASSN AMER NEUROTOLOGY SOCIETY CORNELL MEDICAL COLLEGE DEPARTMENT OF OTOLARYNGOLOGY 1300 YORK AVE UNIVERSITY HOSPITALS 10021 NEW YORK NY IOWA CITY IA 52240 MS CONSTANCE HOLLAREN DR HOWARD N SCHULTZ AMER NURSES ASSN AMER OCCUP MEDICINE ASSN 1030 15TH ST NW 150 N WACKER DR WASHINGTON DC CHICAGO IL 20036 60606 MR JAMES J GARIBALDI AMER OCCUP THERAPY ASSN INC

AMER OIL CHEMISTS SOCIETY
508 S STATH ST 508 S SIXTH ST 6000 EXECUTIVE BLVD #200 ROCKVILLE, MD 20852 CHAMPAIGN IL 61820 ROBERT W HOLLENHORST MD DR LEE W SMITH AMER OPHTHALMOLOGICAL SOCIETY AMER OPTOMETRIC ASSN 200 FIRST ST SW 1730 M ST NW ROCHESTER MN 55901 WASHINGTON DC 20036 MS JOYCE BUCKLER MR. EDWARD J. RENAUER AMER OPTOMETRIC FOUNDATION
EXECUTIVE DIRECTOR
4715 CORDELL AVENUE
WASHINGTON, DC 20014 AMER ORGANIZATION FOR EDUCATION OF HEARING IMPAIRED 3417 VOLTA PLACE NW WASHINGTON DC 20007 DR MARION F LANGER EXECUTIVE DIRECTOR AMER ORTHOPSYCHIATRIC ASSN AMER OSTEOPATHIC ASSN 212 EAST OHIO ST 1775 BROADWAY NEW YORK NY 10019 CHICAGO IL 60611 LEO STEIN DO AMER OSTEOPATHIC COLLEGE OF
ANESTHESIOLOGISTS
2511 KENWOOD LANE
MEMPHIS TN
38134

AMER OSTEOPATHIC COLLEGE OF
FATHOLOGISTS
550 MUNSON
TRAVERSE CITY MI
49684

EXECUTIVE DIRECTOR AMER OSTEOPATHIC HOSPITAL ASSN AMER OTOLOGICAL SOCIETY 930 BUSSE HIGHWAY PARK RIDGE ILL

60068

HAROLD SCHUKNECHT MD 243 CHARLES ST BOSTON MA

WASHINGTON DC

20024

MR IRVING LIEBERMAN AMER PARENTS COMMITTEE

AMER PARKINSON DISEASE ASSN
1346 CONNECTICUT AVE NW
147 EAST 50TH ST
NEW YORK NY NEW YORK NY

10022

DAVID GOLDRING MD

AMER PERSONNEL & GUIDANCE ASSN
ST LOUIS CHILDREN'S HOSPITAL

TOUCH HILDREN'S HOSPITAL

WASHINGTON DC

20009 ST LOUIS MO

63110

20009

AMER PETROLEUM INSTITUTE
1801 K ST NW WASHINGTON DC

20006

AMER PHARMACEUTICAL ASSN 2215 CONSTITUTION AVE NW WASHINGTON DC

20037

AMER PHYSICAL SOCIETY
335 E 45TH ST
NEW YORK NY NEW YORK NY

10017

MR ROYCE NOLAND AMER PHYSICAL THERAPY ASSN 1156 15TH STREET, N.W. WASHINGTON, DC

20005

20015

MELVIN SABSHIN MC AMER PODIATRY ASSN
20 CHEVY CHASE CIRCLE NW
WASHINGTON DC

AMER PSYCHIATRIC ASSN
1700 18TH ST NW
WASHINGTON DC

20009

MS HELEN FISCHER

AMER PSYCHOANALYTIC ASSN

ONE E 57TH ST

NEW YORK NY

DR HENRY P DAVID

AMER PSYCHOLOGICAL ASSN

POPULATION AND ENVIRONM PSYCH

8307 WHITHAN DR

10022 BETHESDA MD

20034

MS BRENDA GUREL

AMER PSYCHOLOGICAL ASSN

PSYCHOLOGISTS IN PUBLIC SVC

1752 LANIER PLACE

DR JOAN HORAI

AMER PSYCHOLOGICAL ASSN

1200 17TH ST NW

WASHINGTON DC 1752 LANIER PLACE
WASHINGTON DC 20008

20036

MR MURRAY ALPERT
AMER PSYCHOPATHOLOG ASSN INC NEW YORK NY 10016

AMER PSYCHOSOMATIC SOCIETY INC 265 NASSAU RE ROOSEVELT NY

11575

MR MICHAEL CARROLL AMER REHABILITATION FOUNDATION
CHICAGO AVE AT 27TH AVE
MINNEAPOLIS MN
ATLANTA GA 55407

ALAN S COHEN MD

MS JOAN K ERPF

ATLANTA GA

30322

DR STEPHEN J JERRICK AMER ROETGEN RAY SOCIETY

AMER SCHOOL HEALTH ASSN
EMORY UNIVERSITY CLINIC

ATLANTA GA

DR STEPHEN J JERRICK
AMER SCHOOL HEALTH ASSN
PO BOX 708
KENT OH KENT OH

44240

DR JEAN D WILSON

MAURICE RAPPAPORT MD

DR ELLSWORTH B COOK AMER SOCIETY FOR

PHARM & EXPER THERAPFUTICS

9650 ROCKVILLE PIKE

BETHESDA MD

20014

AMER SOCIETY FOR ADOLESCENT

FSYCHIATRY

24 GREEN VALLEY RD

WALLINGFORD PA

196 BETHESDA MD

475 WHITE PLAINS RD

10707

DR NANCY L R BUCHER

AMER SOCIETY FOR CELL BIOLOGY

HUNTINGTON LABORATORIES

MASSACHUSETTS GENERAL HOSPITAL

O2114

DR WILLIAM E CONNER

AMER SOCIETY FOR CLINICAL

NUTRITION

9650 ROCKVILLE PIKE

D2570N MA

O2114

DETHESDA MD

200

G BURROUGHS MIDER MD AMER SOCIETY FOR EXPERIMENTAL

PATHOLOGY

AMER SOCIETY FOR HEALTH

MANPOWER EDUCATION & TRAINING 9650 ROCKVILLE PIKE 840 N LAKE S BETHESDA MD 20041 CHICAGO IL

DR AUDREY EVANS DR JEAN D WILSON

AMER SOC FOR CLINICAL INVEST

DEPT OF MED SW MED SCHOOL

UNIVERSITY OF TEXAS

DALLAS, TX

CR AUDREY EVANS

AMER SOC OF CLINICAL ONCOLOGY

CHILDRENS HOSPITAL

34TH AND CIVIC CENTER BLVD

PHILADELPHIA PA

19104

MR DONALD P CLOUGH
AMER SOCIAL HEALTH ASSN
260 SHERIDAN AVE
PALO ALTO CA

94306

PAUL SHERLOCK MD
AMER SOCIETY FOR
GASTROINTESTINAL ENDOSCOPY
1275 YORK AVE
NEW YORK NY
100 10021

AMER SOCIETY FOR
NEUROCHEMISTRY
NONDESTRUCTIVE TESTING
7190 SW 99TH ST
NEW YORK NY
10032
MIAMI FL
33156

JOE W KING MD 19086

MRS KAREN BURKE AMER SOCIETY FOR ADVANCEMENT

OF ANESTHESIA IN DENTISTRY

U75 WHITE PLAINS ED

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AMER SOCIETY FOR ARTIFICIAL

INTERNAL ORGANS

EO BOY 777 FO BOX 777
BOCA RATON FL 33432

20041

DR F GILBERT MCMAHON
AMER SOCIETY FOR CLINICAL
PHARMACEUTICAL THERAPY
PHARMACOLOGY & TEERAPEUTICS
17 18 GALLAGHER RC
CLEVELAND OH
44 106
NORRISTOWN PA
19401

840 N LAKE SHORE DR CHICAGO IL 60611 DR ROBERT F ACKER

AMER SOCIETY FOR MICROBIOLOGY

1913 I ST NW

DENTISTRY

435 N MICHIGAN AVE

606 1913 EYE ST NW 20006

EXECUTIVE DIRECTOR

AMER SOCIETY FOR TESTING AND

MATERIALS

19 16 RACE ST

PHILADELPHIA PA

AMER SOCIETY OF
AGRICULTURAL ENGINEERS
2950 NILES ROAD
ST. JOSEPH, MINNESOTA 49085

MR JOHN W ANDERS

THOMAS B BRADLEY MD AMER SOCIETY OF HEMATOLOGY

VA HOSPITAL 151A

4150 CLEMENT ST

SAN FRANCISCO CA

94121

AMER SOCIETY OF HUMAN GENETICS
JOHNS HOPKINS UNIVERSITY
601 N BROADWAY
BALTIMORE MD

21205

CHICAGO IL 60611

AMER SOCIETY FOR PUBLIC
ADMINISTRATION
CONTROL
1200 CONNECTICUT AVE NW
WASHINGTON DC
20036
MILWAUKZE WI
53 53203

AMER SOCIETY OF
ANESTHESIOLOGISTS
515 BUSSE HIGHWAY
PARK RIDGE IL
60612

AMER SOCIETY OF AGRICULTURAL
ENGINEERS
2950 NILES RD
ST JOSEPH MS
49085

AMER SOCIETY OF AGRONOMY
677 S SEGOE RD
MADISON WI
53711

AMER SOCIETY OF ALLIED HEALTH
PROFESSIONS
ONE DUPONT CIRCLE NW #300
WASHINGTON DC 20036

DR CLAUDE CRUSE

AMER SOCIETY OF ANIMAL SCIENCE

113 N NEIL ST #311

CHAMPAIGN IL

61820

DR RUSSELL J HILMOE

AMER SOCIETY OF BIOLOGICAL

CHEMISTS

9650 ROCKVILLE PIKE

EETHESDA MD

20014

MR WILLIAM F HOFFMAN JR

AMER SOCIETY OF CLINICAL
HYPNOSIS
2400 E DEVON #218
DES PLAINES IL

MR DAVID L GILCREST
AMER SOCIETY OF CLINICAL
PATHOLOGISTS
2100 W HARRISON
CHICAGO IL

60612

MR RICHARD A RUDDY

AMER SOCIETY OF COLON & AMER SOCIETY OF DENTISTRY FOR

RECTAL SURGEONS CHILDREN

6615 GRISWOLD 211 E CHICAGO AVE #920

DETROIT, MICHIGAN 48226 CHICAGO IL 60611

EXECUTIVE DIRECTOR AMER SOCIETY OF INTERNAL MEDICINE 703 MARKET ST #535 SAN FRANCISCO CA 94103

THOROFARE NJ

08086

CHICAGO IL

60611

MRS ANITA SKOLNICK AMER SOCIETY OF PHYSICIAN AMER SOCIETY OF FLANT ANALYSTS 11722 VIERS MILL RD 11722 VIERS MILL RD
WHEATON MD 20902

AMER SOCIETY OF PODIATRIC ASSISTANTS 2204 WASHINGTON AVE WACO TX

AMFR SOCIETY OF RADIOLOGIC
TECHNICIANS
TECHNOLOGISTS
500 NORTH MICHIGAN AVE
CHICAGO IL
60611

AMER SOCIETY OF RADIOLOGIC
TECHNOLOGISTS
500 N MICHIGAN AVE #836
CHICAGO IL
60611

DIV OF DEVELOPMENTAL BIOLOGY AMER SOCIETY OF ZOOLOGISTS MOORPARK CA

93021

AMER SOYBEAN ASSN HUDSON IA

50643

ELLIOT L SAGALL MD AMER SOCIETY OF LAW & MEDICINE 454 BROOKLINE AVE BOSTON MA

02215

LAURENCE E EARLY MD

AMER SOCIETY OF NEPHROLOGY

6900 GROVE RD

NORMAN E LEEDS MD

AMER SOCIETY OF NEURORADIOLOGY

MONTEFIOR HOSP & MED CENTER 111 E 210TH ST NEW YORK NY

AMER SOCIETY OF ORAL SURGEONS

211 E CHICAGO AVE

DP LEON JACOES

AMER SOCIETY OF PARASITOLOGY
FOGARTY INTERNATIONAL CENTER BUILDING 31 # 2CO2 NIH BETHESDA MD 20014

> FHYSIOLOGISTS 9650 ROCKVILLE PIKE BETHESDA MD 20014

LON H COOPER DPM AMER SOCIETY OF FODIATRIC MEDICINE PO BOX 726 76702 SIDNEY OH 45365

60611

AMER SOCIETY OF SANITARY

ENGINEERING

960 ILLUMINATING BUILDING

CLEVELAND OH

DR MARK HOEKENGA

AMER SOCIETY OF TROPICAL

MEDICINE & HYGIENE

FO BOX 46502 PARKSDALE BR

CINCINNATI OH 45246

DR RUSSELL R DYNES AMER SOCIOLOGICAL ASSN 1722 N ST NW WASHINGTON CC

20036

DR KENNETH O JOHNSON AMER SPEECH & HEARING ASSN 10801 ROCKVILLE PIKE ROCKVILLE MD

WASHINGTON DC 20005

MR TORRY M SANSONE

AMER STATISTICAL ASSN

806 15TH ST NW

211 EAST CHICAGO AVE #2110

WASHINGTON DC 211 EAST CHICAGO AVE #2110

60611

DR DONALD F TIERNEY

AMER SURGICAL TRADE ASSN

SUITE 1150

1730 PA AVE NW

WASHINGTON DC

DR DONALD F TIERNEY

AMER THORACIC SOCIETY

DEPARTMENT OF MEIICINE

UCLA MEDICAL SCHCOL

LOS ANGELES CA

90024

MR BOB HICKS

97 207

AMER TINNITUS ASSN
PO BOX 5
PORTLAND OR

AMER TYPE CULTURE COLLECTION
12301 PARKLAWN DR
ROCKVILLE MD ROCKVILLE MD

20857

WILLIAM B GARLICK MD

AMER UROLOGICAL ASSN INC

1120 NORTH CHARLES ST

BALTIMORE MD

21201

DR JAMES H STEELE

AMER VETERINARY EPIDEM SOC

SCHOOL OF PUELIC HEALTH

UNIVERSITY OF TEXAS

77025

AMER VETERINARY MEDICAL ASSN

AMERICAN ASSN FOR

REHABILITATION THERAPY

SCHAUMBURG IL

5977 CARRIAGE DR

MEMPHIS TN MR GLEN RAMSEY REHABILITATION THERAPY INC 38134

MR LAWRENCE A ZUPAN

MR LAWRENCE A ZUPAN

AMERICAN ASSN OF OPHTHALMOLOGY

1100 17TH ST NW

WASHINGTON DC

20036

MR BRUCE BLASCH

AMERICAN ASSN OF WORKERS FOR

THE BLIND INC

1511 K ST NW

WASHINGTON DC

20005

NEW YORK NY

MR RICHARD P MCGRAIL

AMERICAN CANCER SOCIETY

777 THIRD AVE

NEW YORK NY

ALFRED SOFFER, M.D.

AMERICAN COLL OF CHEST PHY

EXECUTIVE DIRECTOR

911 BUSSE HIGHWAY 10017 PARK RIDGE, ILLINOIS 60068

MR FLOYD QUALLS AMERICAN COUNCIL OF THE BLIND AMERICAN FISHERIES SOCIETY 329 WOODBURY LN

TOPEKA KS 66606

5410 GROSVENOR LANE 20014 BETHESDA, MD

MR. WALTER J. UNGER AMERICAN HEALTH PLANNING ASSN
AMERICAN LIVER FCUNDATION
2560 HUNTINGTON AVENUE
SUITE 305
ALEXANDRIA, VA
22303
CHEVY CHASE, MD
20015 AMERICAN NUTRITION RES COUNCIL
ADAMS LABORATORIES, INC
3251 OLD LEE HIGHWAY
FAIRFAX, VA
22030

AMERICAN OPTOMETRIC FOUNDATION
4715 CORDELL AVE
BETHESDA MD
20314

DR CHARLES KIESLER AMERICAN PSYCHOLOGICAL ASSN AMERICAN SOCIETY OF 1200 17TH ST NW WASHINGTON DC

ROBERT G DICUS

AMYOTROPHIC LATERAL SCLEROSIS

SOCIETY OF AMERICA

15300 VENTURA BLVD., SUITE 315

NEW YORK NY SHERMAN OAKS, CA 91403

MRS IRIS SHANNON APHA
PUBLIC HEALTH NURSING SECTION
1015 - 18TH ST NW
WASHINGTON DC
20036

APHA DENTAL SECTION
C/O DEPT OF HEALTH AND HOSP
818 HARRISON AVE
EOSTON MA
023

ARMED FORCES INSTITUTE: OF ARTHRITIS FOUNDATION PATHOLOGY 6825 16TH ST NW

WASHINGTON DC

20306

3400 PEACHTREE RL.,
ATLANTA, GA

MS STEPHENIE TALBOT

DR CHARLES NAM ASA SOC OF POPULATION SECTION ASBESTOS TEXTILE INST., INC FLORIDA STATE UNIVERSITY

MR EDWARD J RENAUER

66 15 GRISWOLE
20036 DETROIT, MICHIGAN 48226 COLON & RECIAL SURGEONS

10021

ANIMAL HEALTH INSTITUTE
SUITE 1009
ADAMS LABS., INC
3251 OLD LEE HIGHWAY
WASHINGTON DC
20006
FAIRFAX, VA
22030

DR. MYRON ALLUKIAN 02118

MS MARGARITA C TREVINO

APHA LATINO CAUCUS

C/O SCHOOL OF NURSING BU

3616 WORTH ST

DALLAS TX

TOM HALL

APHA SECTION ON POPULATION

SCHOOL OF PUBLIC HEALTH

UNIVERSITY OF NO FTH CAROLINA

CHAPEL HILL NC

27514

3400 PEACHTREE RD., NE #101 30326

MR PETER K NEW ARTHRITIS POUNDATION

422 C ST NE

WASHINGTON DC

20002

MR PETER K NEW

ASA MEDICAL SOCIOLOGY SECTION

121 ST JOSEPH ST

TORONTO ON

CANADA M5S 1A 1

TALLAHASSEE FL

32306

FO BOX 224

HATBORO, PENNSYLVANIA 19040

ASBESTOS TEXTILE INSTITUTE ASIAN AMER MENTAL HEALTH PO BOX 471 WILLOW GROVE PA

19090

RESEARCH CENTER 1640 WEST ROOSEVELT RD 60608 CHICAGO IL

ASSN FOR ADVANCEPENT OF BLIND

ASPIRA 6TH FLOOR 6TH FLOUR
22 EAST 54TH ST
10022 JAMAICA NY

MRS ALICE SCCGIN ASSN FOR CHILDREN WITH LEARING DISABILITIES 4156 LIBRARY RD 15234 PITTSBURGH PA

164-09 HILLSIDE AVE

MS MARTHA ROSEN

AND RETARDED

ASSN FOF BEHAVIORAL SCIENCES & MEDICAL EDUCATION HEPSHEY MEDICAL SCHOOL HEPSHEY MEDICAL SCHOOL 17033 HERSHEY PA

> DR SAMUEL MYERS WASHINGTON DC

20009

11432

ASSN FOR CHILDREN WITH
RETARDED MENTAL DEVELOPMENT
902 BROADWAY
LK SAMUEL MYERS
ASSN FOR EQUAL OPPORTUNITY
IN HIGHER EDUCATION
200 S STREET #450 10010 NEW YORK NY

MS CAROLYN GRAVES ASSN FOR GERONTOLOGY IN HIGHER ASSN FOR HOSPITAL MEDICAL EDUCATION ONE DUPONT CIRCLE #520

ISMET KARACAN MD ASSN FOR PSYCHOPHYSIOLOGICAL STUDY OF SLEEP 2002 HOLOMBE BLVD HOUSTON TX

DAVID J LIM MD
ASSN FOF RESEARCH IN COLUMBIA OH

ASSN FOR THE ADVANCEMENT OF
MEDICAL INSTRUMENTATION
AGING RESEARCH
1901 NORTH FT. MYER DRIVE
ARLINGTON, VA
22209
LOS ANGELES CA
900

DOUGLAS H INGRAM MD ASSN FOR THE ADVANCEMENT OF PSYCHOANALYSIS 329 EAST 62ND ST NEW YORK NY

EDUCATION 1911 JEFF TAVIS EIGHWAY #1003 ONE DUPONT CIRCLE #520 1911 JEFF DAVIS FIGHWAY #1003 WASHINGTON DC 20036 ARLINGTON VA 22202

> DR ROGER C DUVOISIN ASSN FOR RES IN NERVEMENT DIS MT SINAI SCHOOL OF MEDICINE 100TH ST AT 5TH AVE 77211 NEW YORK NY 10029

> > JOHN LOTT BROWN PHD ASSN FOR RESEARCH IN VISION AND OPHTHALMCLOGY 4202 FOWLER AVE U OF S FLORIDA TAMPA FL 33620

90007

ASSN FOR THE CARE OF CHILDREN IN HOSPITALS 6900 GROVE RE 10021 THOROFARE NJ 08086

DR ALVIN MORRIS

DR ROBERT L SPROULL
ASSN OF AMERICAN UNIVERSITIES
COMMITTEE ON SCIENCEGRESEARCH
UNIVERSITY OF ROCHESTER
ROCHESTER NY
14627

DR DWIGHT COULTER
ASSN OF AMERICAN VETERINARY
MEDICAL COLLEGES
UNIVERSITY OF GEORGIA
ATHENS GA
3060

ASSN OF CLINICAL SCIENTISTS
DEPT OF LABORATORY MEDICINE
UNIVERSITY OF CONNECTICUT
FARMINGTON CT
06032

ASSN OF FOOD AND DRUG
OFFICIALS
FO BOX 4267
SPRINGFIELD IL 62708

MRS MARGARET RUDOLPH

ASSN OF HALFWAY HOUSE ALC

PROGRAMS OF NORTH AMERICA INC

786 EAST SEVENTH ST

ST PAUL MN

55106

DR LEWIS L CORIEIL

ASSN OF INDEPENDENT RESEARCH

INSTITUTES

COPEWOOD ST

CAMDEN NJ

0810

GEORGE ZUBOWICZ MD

ASSN OF MEDICAL SUPERINTENDENT
OF MENTAL HOSPITALS
BOX 500
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1400 SW 5TH AVE
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DENVER CO
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43215

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UNIVERSITY OF CHICAGO

343 S DEARBOFN ST

CHICAGO IL BRAIN RESEARCH FOUNDATION 60604

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300 LONGWOOD AVE 1001 CONNECTICUT AVE NW
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ASSN OF OFFICIAL ANALYTICAL DR RICHARD J ALLEN CHEMISTS CHILD NEUROLOGY SOCI BOX 540 PEDIATRIC NEUROLOGY BENJAMIN FRANKLIN ST UNIVERSITY HOSPITAL WASHINGTON DC 20044 ANN ARBOR MI

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LOUIS J FILIATRAULT MD SUITE 105

MR LOUIS A ORSINI HEALTH INSURANCE ASSN OF AMER HEALTH INSURANCE INST OF AMER 919 THIRD AVE NEW YORK NY

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MR EDWARD M SALTZMAN HEALTH LEARNING SYSTEMS
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1455 BROAD ST
4211 39TH ST NW 1455 BROAD ST BLOOMFIELD NJ

07003

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HEALTH RESEARCH GROUP WASHINGTON DC

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HELEN KELLER INTERNATIONAL
22 WEST 17TH ST MR HAROLD G ROBERTS NEW YORK NY

HUDSON INSTITUTE QUAKER-RIDGE RD CROTON-ON-HUDSON NY 10520

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HUMAN GROWTH FOUNDATION

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601 LIGHT ST

MR LAURENCE J KANE

HUMAN LIFE FOUNDATION

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1511 K ST, N W , SUITE 601 LIGHT ST 1511 K ST, N W , SUITE 305 BALTIMORE MD 21230 WASHINGTON, DC 20005

WASHINGTON DC

20036

HEALTH CARE MERCY CENTER HEALTH INDUST MANUFACTRS ASSN

 SUITE 105
 SUITE 1100

 3960 COON RAPIDS BLVD
 1030 15TH ST NW

 ANCKA MN
 55303
 WASHINGTON DC
 20005

 SUITE 1100

> 1850 K ST NW WASHINGTON DC

20006

4211 39TH ST NW WASHINGTON DC

20016

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> MS MARIAN KNCWLES HUMAN FACTORS SOCIETY PO BOX 1369 SANTA MONICA CA

90406

MR LAURENCE J KANE HUMAN LIFE FOUNDATION 1511 K ST, N W , SUITE 305

SUITE 305 SUITE 305
WASHINGTON DC 20005

DR CREIGHTON L EDWARDS

MR LAURENCE J KANE
HUMAN LIFE FOUNDATION HUMAN LIFE FOUNDATION OF AMER
1511 K ST NW WASHINGTON CC 20005

DR CREIGHTON L EDWARDS
HUNTINGTONS CHOREA FOUNDATON INDUSTRIAL GAS CLEANING
PO BOX 66704 INSTITUTE
HOUSTON TX PO BOX 1333
77006 STAMFORD CT 06904

INDUSTRIAL HEALTH FOUNDATION INDUSTRIAL RESEARCH INSTITUTE
5231 CENTRE AVE SUITE 2209
PITTSBURGH PA 100 PARK AVE

100 PARK AVE 15232 NEW YORK NY 10017

DR JAY SANFORD INFEC DISEASES SOC OF AMER
UNIFORMED SERVICES UNIVERSITY
6917 ARLINGTON RD
BETHESDA MD
20014
INST DEVELOPMENTAL RESEARCH
CHILDRENS HOSPITAL RES FOUNDAT
ELLAND AVE AND BETHESDA
45229

BETHESDA MD

DR B S SCHWEIGERT

INST OF FOOD TECHNOLOGISTS

221 N LA SALLE ST

CHICAGO IL

60601

INSTITUTE OF ELECTRICAL AND
ELECTRONICS ENGINEERS
345 E 47TH ST
NEW YORK NY

10017

DR EARL WAYNE GRCGAN
INSTITUTE OF FORENSIC MEDICINE
NEW YORK UNIVERSITY MED CENTER
550 FIRST AVE
NEW YORK NY
10016

DR EARL WAYNE GRCGAN
INSTITUTE OF LABORATORY ANIMAL
RESOURCES NRC
2101 CONSTITUTION AVE NW
WASHINGTON DC
20418

THE REVEREND DONALD E SMITH INSTITUTES OF RELIGION AND
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3 W 29TH ST
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10001
INSTRUMENT SOCIETY OF AMER
400 STANWIX ST
FITTSBURGH PA
152

15222

INTER-IND EMISSION CONTROL PRG
SCIENTIFIC RESEARCH STAFF
PO BOX 2053
DEARBORN MI 48121
SAN JOSE COSTA RICA

INTERNATIONAL EYE FOUNDATION

EXECUTIVE DIRECTOR

7801 NORFOLK AVENUE

BETHESDA, MD

7801 MR MICHAEL A CODI

INTERNATIONAL EYE FOUNDATION

7801 NORFOLK AVE

EETHESDA MD

PETHESDA MD 20014

INTERNATIONAL YEAR OF THE INTERNTL SOCIOLOGICAL ASSN CHILD PO BOX 719 STATICN A 10017 866 UNITED NATIONS PLAZA NEW YORK NY

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MR TERRY O ROURKE

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INTL CHILDBIRTH EDUCATION ASSN 11040 BLUE MOUND RD MILWAUKEE WI

53226

DR R BRADLEY SACK INTL CNTR FOR MEDICAL RESEARCH
BALTIMORE CITY HOSPITAL
4940 EASTERN AVE
BALTIMOPE MD
21224

SCHOOL OF PUBLIC HEALTH
TULANE UNIVERSITY
NEW ORLEANS LA
70112

DP ALBERT RUDNICK INTL CNTR FOR MEDICAL RESEARCH INTL CNTR UNIVERSITY OF CA SAN FRANCISCO SUITE 350 SAN FRANCISCO CA 94143

INTL COLLEGE OF APPLIED NUTRITION PO BOX 386 LA HABRA CA 90631

INTL COMMUNICATIONS AGENCY WASHINGTON DC

MONTREAL QUEEEC CANADA H3C2V2

E JAMES ANTHONY MD INTL ASSN FOR CHILD PSYCHIATRY AND ALLIED PROFESS
333 CEDAR ST AND ALLIED PROFESSIONS NEW HAVEN CT 06510

INTL ASSN FOR PARENTS OF DEAF

814 THAYER AVE

STLVER SPRING MD

20901

STERLINGSHEE SCOTLD

INTL ASSN OF REFRIGERATED WAREHOUSES 7315 WISCONSIN AVE WASHINGTON DC 20014

INTL CHIROPRACTORS ASSN 741 BRADY ST DAVENPORT IA

52808

DR THOMAS ORIHEL

DR WILMA DONAHUE INTL CNTR FOR SOC GERONTOLOGY 425 13TH ST NW
WASHINGTON DC 20004

MR IRVING ELUMBERG INTL COMMITTEE AGAINST MENTAL ILLNESS ROCKLAND RESEARCH INSTITUTE ORANGEBURG NY 10962

MRS NANCY LE FEBVRE INTL COUNCIL FOR INFANT SURVIVAL 510 FIFTH ST NW
20547 WASHINGTON DC 20001 INTL COUNCIL OF NURSES
PO BOX 42
CH-1211
GENEVA 20 SHITZERIAND GENEVA 20 SWITZERLAND

MRS KATE KATZKI INTL COUNCIL ON SOCIAL WELFARE 345 E 46TH ST NEW YORK NY

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DR WALTER W HALLAND DR WALTER W HALLAND
INTL EPIDEMIOLOGICAL ASSN
ST THOMAS HOSPITAL MED SCHOOL
LONDON SE1 7EH

INTL FED OF MED STUDENTS ASSN
STENBACKINKATU 9
SF-00290 ENGLAND UK

HELSINKI 29 FINLAND

INTL FEDERATION ON AGING
SUITE 500
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DR GEORGE BLUE SPRUCE INTRA DEPARTMENTAL COUNCIL ON INDIAN AFFAIRS 1832 M ST NW WASHINGTON DC 20036

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JOINT COMMISSION ON

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SUITE 2201 875 N MICHIGAN AVE
CHICAGO IL

A L SAHS MD

JOINT COMMITTEE FOR STROKE
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JUVENILE DIABETES FOUNDATION
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02215

DR RUSSELL G MAWEY
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BATTLE CREEK MI
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20057

MR TALMAGE SIMPKINS LABOR MANAGEMENT MARITIME

COMMITTEE AFL-CIO

100 INDIANA AVE NW

WASHINGTON DC

LASER INSTITUTE OF AMERICA

4100 EXECUTIVE PARK DR

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LEONARD WOOD MEMORIAL FOR THE
ERADICATION OF LEPROSY
2430 PENNSYLVANIA AVE NW
WASHINGTON DC
20037

MS LEE HOFFMAN
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PITTSBURGH PA
152 EDWIN M LERNER II MD

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KENNEDY CENTER FOR RESEARCHKENNEDY CHILD DEVELOPMENT CNTRON EDUCATIONUNIV OF COLORADO MEDICAL CNTRBOX 404200 EAST NINTH AVENASHVILLE TN37203

LA LECHE LEAGUE INTERNATIONAL 9616 MINNEAPOLIS AVE FRANKLIN PARK IL

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600 NEW HAMP AVE NW #600
PITTSBURGH PA 15216 WASHINGTON DC 20418 SOCIETY MR ELLNOR GAMMAGE MR BRIAN O CONNEIL MENDED HEARTS MENTAL HEALTH ASSN 721 HUNTINGTON AVE 1800 N KENT ST ROSSLYN VA ROXBURY MA 02115 22209 MRS LUCILLE RATNER MEPRILL PALMER INSTITUTE MONTGOMERY COUNTY ASSN FOR THE TREE TO THE TREE CHILDREN 71 EAST FERRY AVE HEARING IMPAIRED CHILDREN DETROIT MI 9408 CROSBY RD 48202 SILVER SPRING MD 20910 MR JOHN KNUBEL MR ROBERT ROSS
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LANGUAGE HANDICAPPED CHILDREN 810 SEVENTH AVE

BOX 315

SILVER SPRING MD 20906

NEW YORK NY

DR. CHARLES PAK NAT ASSN PROG DIR OF CLIN RES

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CHEMICALS ASSN

1155 15TH ST NW

DALLAS, TEXAS

75235

NATIONAL AGRICULTURAL

CHEMICALS ASSN

1155 15TH ST NW

WASHINGTON DC

NATIONAL ALLIANCE OF BLACK

SCHOOL EDUCATORS

PO BOX 370

CRAWFORD N.I.

07016

MAS ROWALD DATION

NATIONAL ALS FOUNDATION INC

185 MADISCN AVE

NEW YORK NY

10 PO BOX 370 CPAWFORD NJ 07016

DR JAMES T SPENCER JR

CHARLES F WITTEN MD NATIONAL ASSN FOR SICKLE CELL

NATIONAL ASSN FOR THE ADVANCE

MENT OF COLORED PEOPLE

945 S WESTERN AVE #206

1790 BROADWAY

LOS ANGELES CA

90006

NEW YORK NY

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10010
WASHINGTON, DC
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NEW YORK NY

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DEPARTMENT OF BOTANY

UNIVERSITY OF FLOPIDA

GAINESVILLE FL

32611

MRS SYLVIA N RACHLIN

MYOPIA RESEARCH FOUNDATION

415 LEXINGTON AVE #705

NEW YORK NY

10017

CLEMENT B. SLEDGE, M. D.

NAT ARTHRITIS ADVISORY BOARD

HARVARD MED SCHOCL

125 PARKER HILL AVE

BOSTON, MA

02120

20005

MRS RONALD DRESSEN

PR SAMUEL L MYERS

NATIONAL ASSN FOR CHILD

DEVELOPMENT AND EDUCATION

500 12TH STREET SW #810

WASHINGTON DC

PR SAMUEL L MYERS

NATIONAL ASSN FOR EQUAL

OPPORTUNITY IN HIGHR EDUCATION

2001 S ST NW #450

WASHINGTON DC

20009

10016

DR JAMES T SPENCER JR
NATIONAL ASSN FOR HEARING AND
SPEECH ACTION
B14 THAYER AVE #201
SILVER SPRING MD
DEVELOPMENT
1750 PENNSYLVANIA AVE NW #318
SILVER SPRING MD
20910
WASHINGTON DC
20006

NATIONAL ASSN FOR RETARDED

CHILDREN

2709 AVE E EAST

ARLINGTON TX

MR WEBB SPRAETZ

NATIONAL ASSN FOR RETARDED

CITIZENS

2709 AVE E EAST

ARLINGTON TX

76010

ARLINGTON TX

760 2709 AVE E EAST ARLINGTON TX 76011

MP JAY CHUMM NATIONAL ASSN OF BLACK SOCIAL
WORKERS
HOWARD UNIVERSITY
WASHINGTON DC
1625 I ST NW
WASHINGTON DC
20006

MR FRANK ESPADA
NATIONAL ASSN OF ETHNIC DA
ASSOCIATIONS
1117 19TH ST NORTH #1209
ARLINGTON VA
22209
WASHINGTON DC
20005 MR FRANK ESPADA

MR CONWAY C DOWNING DATE
NATIONAL ASSN OF HEALTH
SERVS EXECUTIVES MR CONWAY C DOWNING JR., J.D.

NATIONAL ASSN OF HEARING & NATIONAL ASSN OF SPEECH AGENCIES
814 THAYER AVE
STLVER SPECIAL SERVICES SILVER SPRING MD 20910

MR THOMAS DELOACH NATIONAL ASSN OF MENTAL HEALTH
INFORMATION OFFICERS
LEWIS CASS BUILDING

NATIONAL ASSN OF NEIGHBORHOOD
HEALTH CENTERS
1625 E ST NW #403 LEWIS CASS BUILDING LANSING MI

THERAPISTS
PO BOX 367
PO BOX 367
WEST COVINA CA
91793
PHYSICIANS
1625 I STREET, N.W.
20006

MR RAY MASTALISH
NATIONAL ASSN OF ANIMAL
BREEDERS
401 BERNADETTE DR PO BOX 1033
COLUMBIA MO 65201

MR RAY MASTALISH
NATIONAL ASSN OF AREA AGENCIES
ON AGING
WASHINGTON DC 20036

DR GEORGE D JACKSON
NATIONAL ASSN OF BIOENGINEERS
S500 WABASH AVE
TERRE HAUTE IN
47803

DR GEORGE D JACKSON
NATIONAL ASSN OF BLACK
FSYCHOLOGISTS
367 FAIRVIEW AVE
ORANGE NJ 07050

NATIONAL ASSN OF COUNTIES

RESEARCH FOUNDATION

1735 NEW YORK AVE NW
WASHINGTON DC

20006

NATIONAL ASSN OF COUNTY HEALTH
OFFICIALS

WASHINGTON DC

20003

NATIONAL ASSN OF HEALTH SERVICES EXECUTIVES 551 5TH AVENUE 551 FIFTH AVENUE NEW YORK, NY 10017 NEW YORK NY 10017

> NATIONAL ASSN OF HOME HEALTH 1156 15TH ST NW #302 WASHINGTON DC 20005

1625 E ST NW #403 48913 WASHINGTON DC 20006

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THERADISTS

DR JAMES S TATE
NATIONAL ASSN OF POSTGRADUATE

WASHINGTON DC 20036 PLAINVIEW NY

ABUSE PROGRAM 500 1612 K ST NW #900 WASHINGTON DC 20006

NATIONAL ASSN OF STATE PUBLIC
HEALTH VETERINARIANS
47 TRINITY AVE SW
ATLANTA GA
30334

MR DAN QUIRK
NATIONAL ASSN OF STATE UNITS
ON AGING
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WASHINGTON DC

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WASHINGTON DC

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MINNEAPOLIS MN MINNEAPOLIS MN

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MR JAMES ABERNATHY II NATIONAL BAR ASSN SAN FRANCISCO CA 94117

MS CARRIE ROGERS NATIONAL BLACK NURSES ASSN
ROOM 318
175 SOUTH MAIN ST
AKRON OH
44308
NATIONAL BRAILLE ASSN
85 GODWIN AVE
MIDLAND PARK NJ

PRESIDENT NATIONAL BUREAU OF ECONOMIC PESEARCH 261 MADISON AVE NEW YORK NY 10016

MR EDWARD F X LAWLOR JR

NATIONAL ASSN OF PRIVATE

PSYCHIATRIC HOSPITALS

1701 K ST NW #1205

WASHINGTON DC

MR CHUCK MERIN

NATIONAL ASSN OF RETIRED

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1533 NEW HAMPSHIRE AVE NW
WASHINGTON DC

20036

JAMES W COUCE NATIONAL ASSN OF SCHOOLS OF
PUBLIC AFFAIRS&ADMINISTRATION
1225 CONNECTICUT AVE NW
1425 OLD COUNTRY RD 11803

DR CARL AKINS

NATIONAL ASSN OF STATE DRUG

ABUSE PROGRAM COORDINATORS

1612 K ST NW #900

MR HARRY SCHNIBBE

NATIONAL ASSN OF STATE MENTAL

HEALTH PROGRAM DIRECTORS

1001 3RD ST SW #113 20024 WASHINGTON DC

20036

20910

NEW YORK NY

10022

DR EUGENE WIGGINS NATIONAL BLACK ASSN OF SPEECH AND HEARING LANGUAGE 14400 INNBROOK CI WHEATON MD 20906

MIDLAND PARK NJ

07432

DR RUSSELL J ARICO NATIONAL CANCER PETITION PO BOX 85 WATERTOWN MA

NATIONAL CANNERS ASSN 1133 20TH ST NW

MR MICHAEL GORMAN

NATIONAL COMMITTEE AGAINST

MENTAL ILLNESS

1101 17TH ST. NE 1101 17TH ST NW WASHINGTON DC 20036

MS MARGARET E BERRY
NATIONAL CONFERENCE ON SOCIAL
WEIFARE
WEIFARE WELFARE

400 FIRST ST NW #706 WASHINGTON DC 20001

EXECUTIVE VICE PRESIDENT NATIONAL COUNCIL OF HEALTH CARE SERVICES 1200 15TH STREET., N. W. 1346 CONN AVE NW #3832 WASHINGTON, DC 20036

1511 K ST NW WASHINGTON DC 20005

DF DELORES DAVIS NATIONAL CENTER ON THE BLACK AGED WASHINGTON DC 20036 WASHINGTON DC 20036

MP TONY MAGGIORE NATIONAL COALITION OF HISPANIC
MENTAL HEALTH ORGANIZATIONS
AND THE ELDERLY
1019 19TH ST NW #730
WASHINGTON DC
20036
MILWAUKEE WI
5323

> 1910 K ST NW 22206 WASHINGTON DC

MS DIANA SCULLY
NATIONAL COMMITTEE FOR NATIONAL CONFERENCE OF STATE
CLINICAL LAB STANDARDS LEGISLATURES
711 EAST LANCASTEP AVE 444 N CAPITOL ST NW 711 EAST LANCASTEP AVE
VILLANOVA PA 19085 WASHINGTON DC 20001

INDIANS

 22 WEST GAY ST
 1430 K ST NW #700

 COLUMBUS OF
 43215
 WASHINGTON DC
 20005

 1430 K ST NW #700

MR MANNY FIERPO HENRY WORK MC
NATIONAL CONGRESS OF HISPANIC NATIONAL CONSORTIUM FOR CHILD
AMER CITIZENS MENTAL HEALTE SERVICES 1800 P ST NW #904 WASHINGTON DC 20009

NATIONAL COUNCIL OF ALCOHOLISM

TWO PARK AVE

NEW YORK NY

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NATIONAL COUNCIL OF COMMUNITY

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NATIONAL COUNCIL OF SENIOR NATIONAL COUNCIL ON DRUG ABUSE
CITIZENS CHICAGO IL

NATIONAL COUNCIL ON RADIATION PROTECTION AND MEASUREMENTS 7910 WOODMONT AVE #1016 WASHINGTON DC 20014

MR ELLARD N JACKSON NATIONAL DENTAL ASSN PO BOX 197 CHARLOTTES VILLE VA

MR TERRY HERNDON
NATIONAL EASTER SEAL SOCIETY
FOR CRIPPLED CHILDREN EADULTS
2023 WEST OGDEN AVE 2023 WEST OGDEN AVE 60612 CHICAGO IL

NATIONAL ENVIRONMENTAL
DEVELOPMENT ASSN
559 NATIONAL PRESS BUILDING
WASHINGTON DC 20045

MR KENNETH JERNIGAN NATIONAL FEDERATION OF THE 524 4TH ST 50309 DES MOINES IA

MRS JUAN SAMPSON NATIONAL FOUNDATION FOR JEWISH GENETIC DISEASES 608 FIFTH AVENUE
10026

MRS JOAN SAMPSON NATIONAL FOUNDATION FOR JEWISH GENETIC DISEASE 608 FIFTH AVE 10026 GENETIC DISEASES

MR DON HELM MR DON HELM NATIONAL GOVERNORS ASSN 400 N CAPITOL ST WASHINGTON DC

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NATIONAL HEALTH COUNCIL 1740 BROADWAY 10019 NEW YORK NY

DP M F BRINK NATIONAL DAIRY CCUNCIL 6300 N RIVER RD ROSEMONT IL

60018

CHILD ADVOCACY PROJECT NATIONAL FASTER SEAL SOCIETY FOR CRIPPLED CHILDREN & ADULTS
14 SOMERSET ST 22902 BOSTON MA 02181

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6 NORTH MICHIGAN AVE
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NORFOLK WAR AND SOUTH MICHIGAN AVE
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20014

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9650 ROCKVILLE PIKE 333 NORTH MICHIGAN AVE CHICAGO IL

60601

MR. CLYDE S. HATCH NATIONAL PHARMACEUTICAL ASSN
REGIONAL DIRECTOR
1601 SOUTH HIGHLAND AVE
LOS ANGELES, CA
90019
NATIONAL PITUITARY AGENCY
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210 FAYETTE ST
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20005

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WASHINGTON DC

20045

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20037

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2808 FEDERAL LANE
BOWIE MD

DR THURMAN S GRAFTON
NATIONAL SOCIETY FOR MEDICAL
RESEARCH SUITE 1100
1000 VERMONT AND NO BOWIE MD

NATIONAL PEST CONTROL ASSN

SUITE 1100

C/O HOWARD UNIVERSITY

8150 LEESBURG PIKE

VIENNA, VA

22180

NATIONAL PHARMACFUTICAL ASSN

C/O HOWARD UNIVERSITY

COLLEGE OF PHARMACY

WASHINGTON DC

200 20001

210 FAYETTE ST BALTIMORE MD 21201

NATIONAL RESEARCH DEFENSE COUNCIL 917 15TH ST NW WASHINGTON DC 20005

WASHINGTON DC

20009

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FOUNDATION

8293 HOMESTEAD RD

BENZONIA MI

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NATIONAL RIGHT TO LIFE COMM

341 NATIONAL PRESS BLDG

529 14TH STREET, N.W.

WASHINGTON, DC

200 20045

MR CHARLES HURLEY

MR ED KING NATIONAL SENIOR CITIZENS LAW 1742 CONNECTICUT AVE NW
WASHINGTON DC
CENTER
1200 15TH ST NW
WASHINGTON DC
20005

AL LANE 1000 VERMONT AVE NW 20710 WASHINGTON EC 20005

10 COLUMBUS CIRCLE NEW YORK NY

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NATIONAL TAY-SACHS & ALLIED
DISEASES ASSN INC
ASSN SUITE 207 122 EAST 42ND ST NEW YORK NY 10017

MR VERNON E JORDAN NATIONAL URBAN LEAGUE
EXECUTIVE DIRECTOR
500 EAST 62ND STREET
NEW YORK, NY 10021

505 NORTHERN BLVD GREAT NECK NY

NATL ENVIRONMENTAL HEALTH ASSN NATURAL FAMILY PLANNING ASSN 80203 1600 PENNSYLVANIA DENVER CO

MRS VIRGINIA S BOYCE

NATIONAL SOCIETY FOR THE

PREVENTION OF BLINDNESS

79 MADISON AVE

NEW YORK NY

MR LOUIS GARCIA

NATIONAL SPANISH SPEAKING

COMMISSION ON ALCOHOLISM

14935 RINALDI ST

MISSION HILLS CA

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MS MARY ANN TUFT
NATIONAL STUDENT NURSES ASSN
NATIONAL SUDDEN INFANT DEATH
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SYNDROME FOUNDATION 310 S MICHIGAN AVE 10019 CHICAGO IL 60604

> 1701 PENNSYLVANIA AVE NW WASHINGTON DC 20005

MR VERNON E JORDAN NATIONAL URBAN LEAGUE 500 E 52ND ST NEW YORK NY

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DR HAROLD ALKSNE NATIONAL WILDLIFE FEDERATION

1412 16TH ST NW

WASHINGTON DC

20036

NATL ASSN FOR THE PREVENTION

OF ADDICTION TO NARCOTICS

175 FIFTH AVE

NEW YORK NY

100 10010

MR ABE HOLTZ

DR CHARLES PAK

NATL ASSN OF PATIENTS ON

HEMODIALYSISETRANSPLANTATN INC

505 NORTHERN BLVD

DR CHARLES PAK

NATL ASSN OF PROG DIRECTORS

GNRL CLINCL RESCH CNTR PROGRAM 5323 HARRY HINES ST DALLAS TX 75235 11021 DALLAS TX

CF CONNECTICUT
FO BOX 250
NEW HAVEN CT 06502

NATURAL RESOURCES COUNCIL OF

AMER SUITE 911

1025 CONNECTICUT AVE NW
WASHINGTON DC

20036

NATURAL RESOURCES DEFENSE
COUNCIL
15 W 44TH ST
NEW YORK NY

10036

DR ARNOLD FREEDMAN
NEUROLOGICAL ASSN
5407 E GRANT B-9
TUCSON AZ

85712

GEORGE EHNI MD
NEUROSURGICAL SOCIETY OF AMER
1531 HERMANN PROFESSIONAL BLDG
6410 FANNIN
77025

NEW YORK ACADEMY OF MEDICINE NEW YORK FERTILITY RESEARCH FOUNDATION 2 EAST 103RD ST NEW YORK NY

FOUNDATION 123 EAST 89TH ST 10029 NEW YORK NY 10028

NEW YORK LEAGUE FOR HARD OF NORTH AMER SOCIETY FOR HEARING PEDIATRIC GASTRONENTEROLOGY
71 WEST 23RD ST 71 WEST 23RD ST NEW YORK NY 10010

SCHOOL OF MEDICINE UNIV OF UT SALT LAKE CITY UT 84132

MS BRITA O'CARROLL NORTH CENTRAL TX COUNCIL OF NORTH WEST CHICANO HEALTH GOVERNMENTS PO BOX COG ARLINGTON TX 76011

ORGANIZATION 909 NE 43RD ST #208 SEATTLE WA 98105

NEW YORK NY 10016

NTL ASSN OF SOCIAL WORK INC

2 PARK AVE
NEW YORK NY

MR CHAUNCEY A ALEXANDER
NTL ASSN OF SOCIAL WORKERS INC
1425 H ST NW #600 WASHINGTON DC 20005

MR PHILLIP A BRIGHT NTL BLACK CAUCUS ON ALCOHOLISM

NTL CONF ON ADMIN OF RES
PARC ALCOHOLISM PROGRAM

DENVER RESEARCH INSTITUTE 1316 ARCH ST PHILADELPHIA PA 19 107 DENVER COLO

2050 E ILIFF AVE 80210

MR JACK OSSOFSKY NTL COUNCIL ON THE AGING INC

NTL GENETICS FOUNDATION INC 1828 L ST NW WASHINGTON DC 20036

MRS RUTH Y BERINI 9 WEST 57TH ST NEW YORK NY

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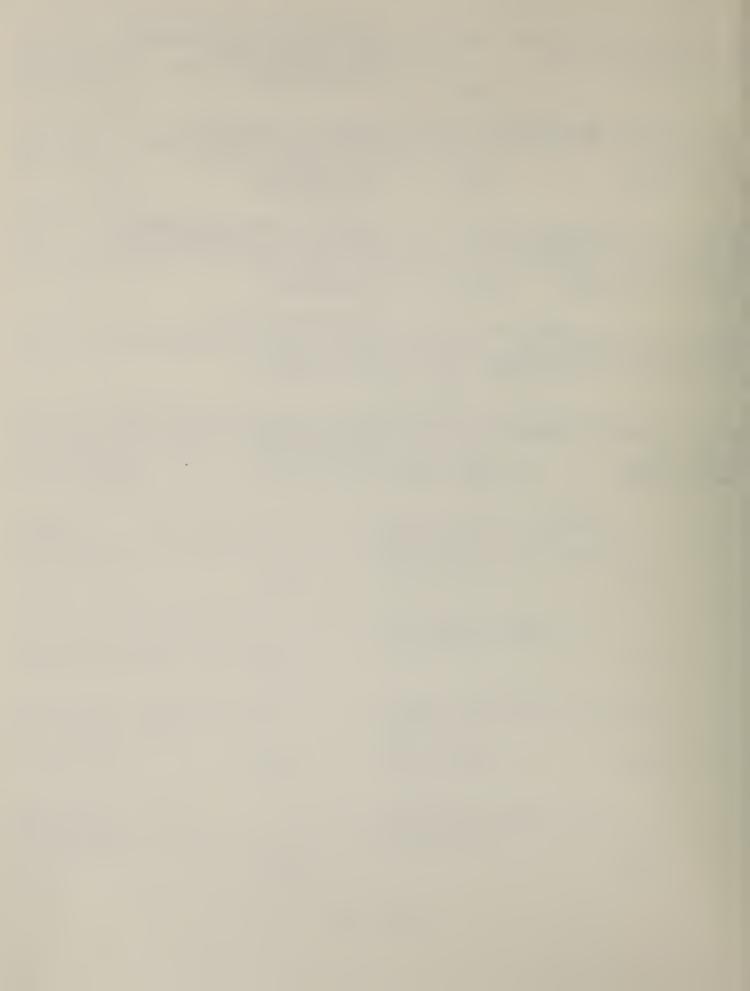
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WORLD HEALTH ORGANIZATION
ADVISORY COMM ON MED RESEARCH
1211 GENEVA 27
SWITZERLAND

HALFDEN MAHLER, M D
WORLD HEALTH ORGANIZATION
1211 GENEVA 27
SWITZERLAND

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APPENDIX B



INTRODUCTION

This Appendix contains the public comments that were considered in the development of the Draft DHEW Health Research Principles presented at the National Conference on October 3-4, 1978. These comments were received in response to Secretary Califano's memorandum of July 19 (reproduced in Volume I). The Secretary's remarks to the Annual Meeting of the American Federation for Clinical Research provided the context for the responses. A list of the approximately 1,000 professional societies and health organizations that were asked for their views and suggestions is contained in Appendix A.

A summary of the general themes suggested in those public comments received by September 1 was prepared and included in the pre-Conference material sent to all those who registered for the National Conference. In addition, copies of the comments on which the summary was based were distributed at the Conference to all participants. This Appendix is organized in alphabetical order by society and includes all comments received through December 1, 1978.



The Alan Guttmacher Institute



August 1, 1978

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Senior Vice President Jeannie I. Rosoff Dear Mr. Secretary:

We welcome the opportunity to reply to your request of July 19, 1978, for suggestions on the principles that should guide the Department's decisions on a multi-year strategy for support of health research.

We agree that there has been a dangerous reduction in federal support of health research since 1970 and urge that this trend be reversed. Within that general direction, however, we would urge strongly that the balance of emphasis in health research be shifted to devote more resources to areas that have thus far received scant support, such as:

1) Sexual behavior, fertility regulation and human reproduction-These areas of inquiry have traditionally been scanted as a result of the bias built into medical research toward "diseases" and of taboos that have surrounded the related human and social processes involved. Yet they are crucial areas of life affecting literally everyone individually and our society as a whole. (The very significant effects on both individuals and society of teenage pregnancy, which illustrate the point sharply, have only begun to be recognized in the last several years, largely as a result of your efforts). As Andre Hellegers has repeatedly argued, the present unbalanced emphasis on research into diseases affecting the end of life has to be turned around and greater emphasis placed on research into processes affecting the beginning of life. We would begin that where it begins--with research into the initiation of sexual activity and the development of safe, acceptable and reliable means of regulating pregnancy--and then follow with research into subsequent processes -- abortion or gestation, fetal development, delivery, and infant and early childhood. The emerging science of genetics offers great promise for reducing some of the most terrible health and social problems affecting parents and children for their entire lives and it should have a large role in the new initiative we would urge. The importance of these studies for helping childless couples to have babies they want has just been demonstrated in the success of Steptoe and Edwards' work, initiated in the early 1960s with support from the Ford Foundation's contraceptive research program.

^{*}Member of Executive Committee

We recognize that you have already moved in this general area by recommending the first sizable increase in the budget for NICHD's Center for Population Research and Center for Mothers and Children. We are suggesting that this initiative be followed up with a stategy and a plan to expand this part of the federal research effort so that within five years, its level of support is commensurate with that of the cancer research effort.

- 2) Behavioral research—The behavioral dimension in health problems is also now being recognized, but there is much that remains to be determined before effective means are at hand to deal with these factors. We would urge expansion of support for social science research as an integral part of the federal health research effort. It is already a critical part of the population research program of CPR and needs to be expanded. (It is remarkable, for example, that with all of the current concern over the plight of the family, there is as yet no research studying the extent to which teenage pregnancy contributes to the social problems that are later described as indicators of families in crisis.)
- 3) Health services research—The health services research supported by DHEW thus far has almost exclusively focused on cost-containment. We believe that there is much more to examine. Our work in fertility control over the last 10 years has demonstrated that what health institutions and professionals do is probably the most decisive factor in whether or not some groups receive and use fertility control services and have abortions or unwanted babies. We believe that similar studies would show similar results in other areas of health care. Since it is far easier for the government to influence the supply of health services—their availability and accessibility—than to influence the behavior of individuals, such research could point the way toward solutions for many intractable health problems.

We hope these suggestions are helpful and look forward to seeing the proposed principles which will be developed for the NIH Conference in October.

Sincerely.

Frederick S. Jaff

President

FSJ/meh

CC: Philip A. Corfman, M.D. Norman Kretchmer, M.D.



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August 8, 1978.

Joseph A. Califano, Jr., Secretary
Department of Health, Education and Welfare
Washington, D.C. 20201

Dear Mr. Califano

This is in response to your memorandum of July 19 addressed to "professional Societies and Health Organizations."

The enclosures will provide information concerning AAI and include a program for the Seventh Annual Academy to be held in St. Louis this week. The contents of your memorandum will be discussed at the annual business meeting of the AAI Board of Trustees. A more formal and detailed reply will be sent you thereafter.

Better yet, you, Mr. Secretary, or a duly appointed representative, would be most welcome to attend and to participate in this most important international convocation. It is certain that the AAI Board will wish to be present and participate at the National Conference of October 3-4. Please send a copy of the "proposed principles" mentioned in your memorardum.

Please be assured that we too attach great importance to these questions, and are very anxious to collaborate with all who seek salutions consonant with the intrinsic value of human life.

Yours sincerely in the continuing SERVICE of LIFE

Loté maur

Lore Maier, (Mrs.) Executive Director





2420 Pershing Road Kansas City, Missouri 64108

(816) 474-5720

August 9, 1978

Joseph A. Califano, Jr. Secretary Department of Health, Education, and Welfare Washington, D.C. 20201

Subject: HEW Multi-Year Strategy for Support

for Health Research

Dear Secretary Califano:

On behalf of the American Academy of Nursing please accept my compliments for your concerns and interest in health researck Our comments and recommendations are included under each of your principles.

Throughout its history, nursing has been involved in providing quality care to the American people. Nurses have always shared in the activities of research, especially medical research through their daily reporting of observations and record-keeping. But scientific investigation by nurses themselves is a relatively new field, dating back only to the early fifties.

<u>Principle 1</u>: To maintain at a high level and to enhance our support for fundamental research into biology and behavior.

According to Abdellah and Levine, the first organized and continuing effort to do studies of nursing on a nationwide basis was in 1949 when the Division of Nursing Resources of the U.S. Public Health Service was established to carry out research and consultation in nursing. Since that time, emphasis has been placed on the preparation of the nurse scholar, or the nurse investigator, in research to improve the quality of patient care.

TREASURER

Abdellah, Faye and Levine, Eugene. Better Patient Care Through Nursing Research. New York, Macmillan, 1965, p.3



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(816) 474-5720

-2-

The American Academy of Nursing views the support of this first principle as including research in nursing since nurses provide most of the direct and continuous care to people.

<u>Principle 2</u>: We must assure that there are ample opportunities

for young investigators.

The Academy is in full accord with this principle to the extent that one of the criteria for admission to the Academy is that the candidate has made research contributions beyond the masters thesis or doctoral dissertation and gives evidence of potential to continue to make contributions to nursing. Youth is implied and recognized.

Principle 3: Basic research has to be accompanied by vigorous,

thoughtful and, where appropriate, interdisciplinary application.

Because doctoral programs in nursing are fairly young -- from seven (7) five years ago (1973) to only 19 today, most of the approximately 1,800 nurses with earned doctorates (0.18 percent of the total) received theirs in other disciplines, especially in the social sciences such as sociology, psychology, anthropology. So this principle is in keeping with how nurse investigators have been and are using the interdisciplinary approach in research.

Research in nursing addresses the human and behavioral questions that arise in the treatment of disease, the prevention of illness, and the maintenance of health. The thrust of interdisciplinary involvement is a reality in nursing. Nurse researchers investigate the area of knowledge where the physical and behavioral sciences meet and influence one another.

<u>Principle 4</u>: Our government-supported research must have a strong orientation toward improving the quality of our nation's health and effectiveness of this nation's health services.



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(816) 474-5720

-3-

"Nursing Research Funds Inadequate" was the title of an article in the October 17, 1975 issue of The American Nurse. Testifying before the President's Panel on Biomedical Research on September 30, 1975, representatives of the American Nurses' Association Commission on Nursing Research pointed out that for nursing care to improve, "adequate nursing research must be carried out to provide increased knowledge and sound data on which nursing practice can be based." The following year, 1976, the Association identified priorities for nursing research for practice and for the profession. In keeping with the fourth principle, they are presented here:

PRACTICE

Studies to reduce complications of hospitalization and surgery (sleep deprivation, anorexia, diarrhea, neurosensory disturbances, respiratory infections, circulatory problems, and others).

Studies to improve the outlook for high risk parents and high risk infants.

Studies to improve the health care of the elderly.

Studies of life-threatening situations, anxiety, pain and stress.

Studies of adaptation to chronic illness and the development of self-care systems and group care systems.

Studies to facilitate the successful utilization of new technological developments in patient care.

Studies of nursing interventions to promote health.

Studies to facilitate the successful application of new knowledge to patient care.

The American Nurses' Association. Priorities for Research in Nursing, Kansas City, Mo., The Association, 1976.



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-4-

Studies to define and delineate healthy states.

Studies of addictive and adherence behaviors.

Studies of under- and over-nutrition.

Studies to evaluate the outcomes and/or effectiveness to consumers and providers of different patterns of delivery of nursing services.

PROFESSION

Studies of manpower for nursing education, practice, and research.

Studies of quality assurance for nursing and studies of criterion measures for practice and education.

Studies of the cost effectiveness of nurse utilization and preparation in relation to: acute care, long term care, extended care and community health.

Studies in the history and philosophy of nursing.

Studies of nursing curriculum.

Studies of the organization of the nursing profession.

The Academy believes that these priorities, which have been and are being observed by nurse investigators, are justified for government support in terms of the quality of our nation's health and effectiveness of this nation's health services.

Principle 5: HEW-supported research must be more effectively oriented to develop knowledge bases that support not just some but all the health missions of the Department -- prevention, delivery, regulation, standard-setting, and cost control.

VICE PRESIDENT

TREASURER

Mary Elizabeth Carnegie, D.P.A.



2420 Pershing Road Kansas City, Missouri 64108

(816) 474-5720

-5-

The American Academy of Nursing is in complete agreement with this principle, especially the development of knowledge bases that support all of the health missions of the Department, including nursing. We were pleased to note that the 1977 report of the National Research Council Committee on a Study of National Needs for Biomedical and Behavioral Research states that "nursing research is properly regarded today as a distinct area of scientific inquiry."

We would further like to encourage diversity in research and for promoting creative research, rather than solely for targeted research.

We feel that vision is needed to provide research opportunities for all the health professions and related allied fields.

We wish you well in all your endeavors, and would greatly appreciate having a copy of your proposed principles.

If we can be of any further assistance, please contact us.

Most sincerely,

Sonne C. Aguilera

(Mrs.) Donna C. Aguilera, Ph.D., F.A.A.N. President, American Academy of Nursing

3924 Dixie Canyon Avenue

Sherman Oaks, California 91423



American Academy of PHYSICAL MEDICINE and REHABILITATION

30 North Michigan Avenue

Chicago, Illinois 60602

Telephone: (312) 236-9512

November 6, 1978

Mr. Joseph Califano Secretary Department of Health, Education & Welfare Washington, D.C.

Dear Mr. Califano:

As President of the American Academy of Physical Medicine and Rehabilitation, I am writing to you in advocacy of a multi-year comprehensive strategy for support of Health Research. I am particularly concerned that Rehabilitation Research be brought into the forefront of this effort in order to insure the nation's capability to meet the needs of the disabled and handicapped.

Long range stability and predictability of Federal investments in basic and applied research serve as the key to meaningful results and better utilization of already limited financial resources. Research requires long term commitments on the part of both individuals and institutions and therefore should not be subjected to fluctuations caused by annual funding cycles.

Rehabilitation sorely needs this commitment because of medical technological advances, individuals that heretofore would never have survived are living but are continually confronted with the inability of socio-political-economic systems to adapt and respond to their specific needs. Therefore, greater priority must be given to problemoriented research in this area.

Research must not only deal with developing technologies and techniques at this point, but also with: 1) Outcome studies to examine ways in which rehabilitation can provide alternatives to long term institutionalization in cost effective manners, 2) Ways to close gaps in service systems in the community in serving the long term patient, 3) Measures of functional ability and qualities of life that need to be more widely applied in order to provide more accurate health care and rehabilitation performance.

Rehabilitation research, inspite of the inability today to cure such disorders as stroke or spinal cord injury can enable many individuals to be rehabilitated to enjoy productive and useful lives. Although rehabilitation efficacy has been demonstrated on a single case basis, there remains a need to fund projects associated with data collection and analysis in order to design appropriate systems to accommodate large communities of actual or potential rehabilitation candidates. This genre of investigation will bolster the efforts in basic research.

In addition, since market forces often are contradictory to the successful marketing of rehabilitation research generated technologies (which have the potential to be independence granting and labor saving), government intervention in the form of promotion through subsidies could start the momentum necessary to reach those in need. It is anticipated that in these instances cost benefit analysis for these technologies could be demonstrated.

Rehabilitation research has often been multidisciplinary since the nature of the problems are multifaceted. Not only do the various medical specialties that interface with physical medicine interact in this research, but the incorporation of allied paraprofessional efforts are present as well. In essence rehabilitation is a multi- and interdisciplinary process.

It is in this light that respectfully urge you to consider continued and enhanced support of present and projected Rehabilitation Research Programs.within a framework permitting continuity of effort and long term planning.

Sincerely yours,

Joseph Goodgold, M.D.

President

JG:jm

American Academy of Physician Assistants

2341 Jefferson Davis Highway, Swite.700 Arlington, Virginia 22202 703 / 920-5780

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Harold A. Zintel, M.D. Chicago, Illinois

August 7, 1978

Joseph A. Califano, Jr., Secretary Department of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

Your recent memorandum to professional societies and health organizations requesting input into the development of a multi-year strategy for Federal support of health research was read with considerable interest.

It has become increasingly apparent that the financial resources available to the government are quite limited when considering the enormous and varied needs of our society. The comments in your address before the American Federation for Clinical Research clearly pointed out the government's growing participation in the resolution of the dilemmas created by these needs and limited resources.

It seems appropriate, therefore, that any proposal for a multi-year strategy for the support of research activities begin with an indepth review of health dollar allocation across all HEW agencies. Included in the process should be a determination of the percent of dollars devoted to education, services delivery, health services research and life sciences research. With the above completed, those dollars allocated especially to health research should be further categorized by duration and amount of award, investigator status, subject area and the relationship of each to existing health care issues. These data could then serve to determine possible dollar amounts for future awards to be made available to young investigators through a form of "health research fellowship program."

The income data generated also lends itself to being used to determine whether funds ought to be redistributed across agencies or from one program to another in the same agency. An additional outgrowth of the analysis could be the establishment of a policy on institutional cost sharing for supplies, computer services and especially equipment.

American Academy of Physician Assistants

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Daniel R. Thomas American Hospital Association

Harold A. Zintel, M.D.

Chicago, Illinois

Joseph A. Califano, Jr. August 7, 1978 page 2

A committee of experts should simultaneously study the interrelationships between current funding priorities and existing major health care issues. The objective would be to identify questions surrounding each issue and priority that might serve as criteria for the allocation of future research funding. The taxpayers' reluctance to shoulder escalating costs suggests an emphasis in those areas most apt to reduce both illness and health care costs.

While the above suggestions are directed at providing structure for the identification of priority issues, the review of proposals and the allocation of funds, it is uncertain how such an approach will affect the pressures that attend the distribution of research dollars from such groups as consumers, health professionals, the research community, and the government. Surely, the opportunity to participate in the design of a multi-year plan ought to somehow reduce the pressure.

As a young profession, we greatly appreciate the opportunity to participate in the shaping of future Federal policies related to health research.

Respectfully,

C. Emil Fesser, PA-C, Co-Chairman Research and Review Committee

AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE



4720 MONTGOMERY LANE, SUITE 609, WASHINGTON, D. C. 20014

301 -- 654-5600

August 24, 1978

The Honorable Joseph A. Califano, Jr. Secretary of the Department of Health, Education, and Welfare Washington, D. C. 20201

Dear Mr. Secretary:

The American Association of Colleges of Osteopathic Medicine commends the President, you and the National Institutes of Health for the Federal commitment to health research consistent with fiscal reality.

In order to attempt to provide a comprehensive response to the issues raised by your letter of July 19, 1978, and your speech to the American Federation for Clinical Research, the Association convened a conference on the future of Federal support for health research. The results of that conference are embodied in this correspondence.

I believe that the positive reaction that was received when we called this meeting demonstrates the commitment of the colleges -- and the profession -- to a strong research orientation which is inseparable from clinical application and educational philosophy and practice. Such orientation and commitment are not only desirable but fundamental to the enhancement of the understanding of the osteopathic medical philosophy of structure/function interactions, musculoskeletal interrelationships, and the concept that the human body is capable of health maintenance.

At the outset, the Association would like to state that it wholeheartedly supports the concept of developing a multi-year strategy — such as five years — to guide the distribution of limited Federal health research funds. In addition, in reviewing President Carter's FY 1979 budget message to Congress, we were extremely heartened to note that he seeks to halt and reduce the downward drift in Federal support for biomedical research. Since 1969, the number of colleges of osteopathic medicine has increased from five to fourteen. The research programs of these institutions, which produce a significant number of family physicians,

The Honorable Joseph A. Califano, Jr. August 24, 1978
Page Two

need support, especially for those "young squirts" whom we term "young/new investigators."

Principle I

Maintain at a High Level and Enhance Support
for Fundamental Research into Biology and
Behavior

The Association is convinced that quality fundamental research into biology and behavior should not only be maintained but encouraged by the Federal government.

The first dimension you enunciated highlights an aspect particularly important to institutions and disciplines which have not traditionally received significant Federal biomedical research support. The young and/or new investigator -- as well as the biomedical research community and the public -- deserve the freedom to pursue a diverse array of research topics. believe that the new and/or smaller institutions are a vital component in the research community. The Biomedical Research Development Grant (BRDG) program is a good example of the type of programs which permit smaller and/or young institutions to develop quality research programs. Colleges of osteopathic medicine hope to receive funding under this authority in the near future. However, programs such as BRDG require adequate funding, which we would expect will be addressed during the formulation of the multi-year strategy. Within the context of such support there needs to be more diversity in the types of subjects supported. While we do not disagree with the importance of research into the population-based life sciences, we strongly believe that other research in such subjects as alternative methods of dealing with the disease processes as they relate to structure and function, quality of life, and well care versus disease care also need identification and support. In addition, we are not convinced that biostatistics should be placed in this category. It is our belief that HEW should consider separate funding for biostatistics which would dictate its removal from the basic research function.

Relative to the President's desire to halt and reverse the downward drift in Federal support for biomedical research, we note The Honorable Joseph A. Califano, Jr. August 24, 1978
Page Three

that two subsets of this drift deserve reversal also: 1) the downward drift in support of basic (untargeted) research while applied (targeted) research has risen, and 2) the downward drift in support of direct (investigator-controlled) costs of research while the indirect (administrator-controlled) costs have risen.

The Association would like to underscore the necessity of reversing the trend of reduced Federal support for new equipment and facilities and for upgrading existing plants. New capital expenditures are vital to developing institutions, such as colleges of osteopathic medicine, where funds which could have been directed into research activities in the past were traditionally directed into family medicine teaching and clinical programs.

Finally, in order to encourage new/young investigators, NIH should consider increased postdoctoral support for smaller and/ or developing institutions where new investigators could develop more easily while, at the same time, providing research stimulation for these institutions.

In this context, we believe that the colleges of osteopathic medicine can offer alternative and creative approaches to research and the treatment of disease as well as alternative perspectives on health care and physiological function which would provide excellent training for the new physician and basic scientist. This approach would address the enunciated goal of providing more diversity of outlook in the biological sciences. Our suggestions are made to emphasize the need for broad and equitable distribution of research activities without sacrificing quality.

Principle II Assure Ample Opportunities for Young Investigators

Previous comments have expressed our total agreement with this second principle. There must be the assurance of ample opportunities for truly innovative investigators. Currently the quenching effects of age are matched by the squelching effects of conformity. The new/young investigator -- be it the individual or the institution -- must have adequate increases in

The Honorable Joseph A. Califano, Jr. August 24, 1978
Page Four

the number of opportunities for initiating research. Increasing the small research grant pool for new/young investigators is one alternative. In addition, it would be worthwhile, as stated before, to support more postgraduate research programs, especially at smaller institutions. In supporting the second principle, we envision not only the need for seed money for these young investigators, but a commitment that the program and the funds are part of a multi-year strategy. There is the need for the new/young investigator to sense both a moral and a monetary commitment by the Federal government and the institution so that a true research environment is created. Further, single and/or young investigator grants need further support so that smaller and new institutions can begin to impact in the research arena.

In addition, peer review committees and NIH in general must acknowledge the <u>bona fide</u> research capabilities of even the newest and smallest institutions, if there are to be the serendipitous opportunities which the Federal government and the public anticipate.

Principle III Basic Research Has to be Accompanied by Vigorous, Thoughtful and, Where Appropriate, Interdisciplinary Applications

At the onset, the Association believes that this principle states very clearly the unique contributions colleges of osteopathic medicine make to basic research. Small institutions have fewer barriers to leap and provide a uniquely different milieu for the emergence of creativity than many larger institutions. The philosophy of osteopathic medicine provides opportunities for a physician to return to school, interact with the research and with the possibility of implementing research in his or her clinical practice. We advocate interrelationships between basic and applied research as well as among research disciplines. New ways of supporting these interrelationships are essential if research is to be creative and innovative. One good way to achieve this would be for NIH to support more interdisciplinary seminars with established and new/young investigators as participants.

The Honorable Joseph A. Califano, Jr. August 24, 1978
Page Five

Principle IV

Government-Supported Research Must Have a
Strong Orientation Toward Improving the
Quality of the Nation's Health and the
Effectiveness of the Nation's Health
Services

One of the major problems which the osteopathic profession believes should be addressed more adequately is how to convince an individual of his or her own responsibility for good health. Health care research must be directed into projects which can assist in developing mechanisms to demonstrate to individuals that proper health maintenance is preferable to disease care.

One of the dilemmas which is faced is how to translate the data of basic health care research into gains in patient well-being. Research needs to be done in this area. Demonstration grants for targeted populations which emphasize research into uncovering the differential vulnerabilities of individuals to health and disease are a possibility. In other words, research should increasingly be directed to health care and maintenance rather than to disease care.

Implicit in the fourth principle is the need to understand and incorporate into all medical education and research a reorientation of some traditional goals of health and research. Answers to questions such as "Why do people stay healthy?" should be addressed. Should there be reorientation within the health care research community to maintaining proper health rather than the current emphasis on disease? Are there methods or combinations of methods of treatment which improve health, reduce hospitalization, and contain or reduce costs?

We are interested in positive health maintenance research. In order to explore fully possible areas there must truly be the opportunity for innovative research activities.

Principle V

HEW-Supported Research Must be More

Effectively Oriented to Develop Knowledge

Bases Supporting All the Health Missions

Of the Department

This principle acknowledges the need to reallocate Federal health

The Honorable Joseph A. Califano, Jr. August 24, 1978
Page Six

dollars into all health missions of the Department. We firmly support the approach of increasing and restoring the Federal commitment to basic research. We also believe that all Federal research components must be acutely aware of new and possibly misunderstood knowledge bases which may offer solutions to health care problems and to the attendant costs. Advisory committees must now, more than ever, be diligent in reviewing proposals which may offer such solutions. The composition of these bodies must include osteopathic representation in order to ensure that the same diversity which the Department has heretofore encouraged in all phases of professional research will be maintained in the peer-review process.

We appreciate the opportunity to address the critical issues raised in your letter and speech and look forward to the National Conference with a sense of increased commitment to the overall cause of better health care.

Singerely

Anthony J. McNevin Executive Director

cc:

Donald S. Fredrickson, M.D. Director, National Institutes of Health

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AJM: mcw

1625 MASSACHUSETTS AVENUE, N.W. ASSOCIATION WASHINGTON, D.C. 20036

202/667-9433

August 8, 1978

Mr. Joseph A. Califano, Jr. Secretary Department of Health, Education, and Welfare Washington, D. C. 20201

Dear Mr. Califano:

Thank you for the letter of July 19 indicating that a multiyear strategy to guide the allocation of government research dollars was being developed and our views on the principles that should be included.

We have reviewed the general principles that were included in your presentation to the American Federation for Clinical Research and believe that they contain the general issues of concern to the scientific and academic communities. Each of the principles contains several relevant issues that are important to the research community, and we believe should be included when the final principles are adopted.

Because we have not been able to obtain information on the status of the development of the principles, we are unable to comment, except to agree generally with the approach contained in your presentation. When it is possible to review the material prepared by Dr. Fredrickson and his staff, we will comment further.

Sincerely yours,

W. Bruce, Jr., D.D.S.

Executive Director

HWB/djq

cc: Dr. James H. McLeran

Dr. John W. Hein

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1603 Orrington Avenue, Suite 1160 Evanston, Illinois 60201 (312) 491-9091

JAMES L HANSEN, M.D. Associate Director

August 1, 1978

Joseph A. Califano, Jr., Secretary Health, Education and Welfare 200 Independence Avenue S.W. Washington, D.C. 20201

Dear Mr. Califano:

I am responding to your memorandum of July 19, 1978 regarding professional societies and health organizations. Thank you for including the American Board of Medical Specialties as an addressee and an organization with great interest in health, health care delivery and health research.

Although your memorandum and remarks have not been discussed by the ABMS membership, it is my personal view that the development of a Multi-Year Strategy to guide the allocation of limited government health research dollars is not only timely, but it is desperately needed. Also, it is my personal opinion that HEW-supported research should have a serious and critical examination to eliminate studies that are endless and without application for health problems. Your fifth and final principle requires highest priority.

It is requested that a copy of the proposed principles that will be developed for presentation to a National Conference on October 3-4, 1978 be sent to the ABMS for review prior to the Conference.

Thank you for sharing this important information.

Yours truly,

James L. Hansen, M.D.

Associate Director

JLH/jem

Office of the Chairman of the Board Roberta I. DeVito



American Brittle Bone Society, Inc.

712 Dartmouth Avenue, Cinnaminson, New Jersey 08077

1800 Douglas Avenue South Minneapolis, Minnesota 55403 August 9, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

I am responding on behalf of the American Brittle Bone Society to your July 19 memorandum concerning the development of an over-all strategy for H.E.W. support of health research. I strongly suggest that the following principles be emphasized in formulating your department's strategy.

- Highest priority should be given to increasing support in areas of basic research -- that is, the kinds of research aimed at providing a clear understanding of disease mechanisms. As Dr. Lewis Thomas points out in the attached material, by far the most effective and economical answers to major health problems have come and will undoubtedly continue to come through basic biomedical research. Brittle bone diseases such as osteogenesis imperfecta and osteoporosis offer good examples of the costliness of what Dr. Thomas calls "nontechnology" and "halfway technology". The many expensive hospitalizations, surgeries, and therapies which now constitute health care for the osteogenesis imperfecta patient do nothing to alter the basic disease: the bones still fracture, deformities occur, growth is stunted, and the person remains severely disabled. The only prospect of alleviating the suffering and reducing the costs lies in new knowledge gained through basic research. As you have said, it was foolish to cut back on funding for biomedical research during the past decade. By the same token, it would be prudent to substantially increase basic research funding in the future.
- 2. I agree with the second principle you stated last April -- that research opportunities should be provided for young investigators.
- 3. Basic research should be followed up with attempts to apply the new knowledge. However, scarce federal dollars otherwise available for basic research should not be directly used for large-scale testing programs or for similar types of efforts which resemble health care more than health research. Also, funds available to support basic research should not be the means by which an institution upgrades its physical plant.

Office of the Chairman of the Board Roberta I, DeVito



American Brittle Bone Society, Inc.

712 Dartmouth Avenue, Cinnaminson, New Jersey 08077

- 4. With regard to the National Institutes of Health, care should be taken not to dilute or divert its current basic research focus. The N.I.H. should be kept essentially free from responsibility for health care functions.
- overconcentrated in some areas at the expense of others, an effort should be made to bring the neglected areas into balance. Last year's Senate Appropriations Committee Report indicated that perhaps a disproportionately large share of the N.I.H. budget had been devoted to cancer research and research on heart, lung, and blood diseases. The same report pointed out inadequacies in the funding level of the N.I.A.M.D.D. which (the report said) "conducts and supports research to ameliorate or prevent a wide range of diseases comprising our most prevalent and crippling chronic afflictions." Priority in research should be redirected toward severely disabling genetic diseases.
- 6. The preferred method of supporting basic biomedical research should be through direct research grants rather than through contracts or maintenance of centers, so that maximum freedom and creativity can be fostered, within the limits established by priority guidelines and peer-review procedures. As you mentioned, the government "cannot program or neatly order the mysterious and serendipitous ways in which new knowledge is developed."

I hope the above comments will be of some help to you in formulating your department's new health research strategy. Please send me as soon as possible a copy of the proposed principles to be presented at the October conference.

Thank you.

Sincerely,

John S. Mandeville

President

American Brittle Bone Society

CHONOLOGY CHONOL

American College of Cardiology

HEART HOUSE 9111 OLO GEORGETOWN ROAD BETHESOA, MARYLAND 20014 (301) 897-5400

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August 10, 1978

Secretary Joseph A. Califano, Jr. Department of Health, Education, and Welfare
200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Mister Secretary:

Your memorandum of July 19, 1978 to the Professional Societies and Health Organizations concerning "HEW Multi-Year Strategy for Support for Health Research" is hereby acknowledged. We had earlier received a request from the National Institutes of Health to express our views on this subject. Please see attached our response to Dr. Levy.

The American College of Cardiology greatly appreciates this opportunity to provide opinion concerning this most important subject of health research.

Sincerely,

Leonar 2 5. Dreifus

Leonard S. Dreifus, M.D., F.A.C.C. President

LSD:sk

Enclosure

cc: Raymond D. Cotton, J.D.



American College of Cardiology

HEART HOUSE 9111 OLD GEORGETUWN ROAD BETHESDA, MARYLAND 20014 (301) 897-5400

August 2, 1978

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Executive Director
WHILIAM D NELLIGAN, CAE

Associate Director
UWIGHT C MANAGENTI, Ed D

Robert I. Levy, M.D., Director National Heart, Lung, and Blood Institute National Institutes of Health 9000 Rockville Pike Bethesda, Maryland 20014

Dear Dr. Levy:

The following represents a position paper in response to your request to provide input for the development of a National Conference to establish research planning principles as a prelude to the drafting of a comprehensive multi-year health research plan. We have asked our Board members and officers to express their views for this most important undertaking.

The College is extremely interested in the development of this conference, and the establishment of the principles that will guide a comprehensive multi-year health research plan. The College is dedicated to excellence in research and particularly to excellence of medical care that would result from a comprehensive research plan. We wish to be invited to any and all conferences where you feel we can contribute, and to send our representatives to be appraised of the activities of the task forces and conferences.

The members of the College find themselves in remarkable agreement with the policy statements of Secretary Califono. We all appland the recommendations for fundamental research carried out by young investigators adequately supported for an adequate period of time. There is nothing in his speech that the College could take issue with.

We are particularly in agreement with the concept of stability and long-term support of both projects and individuals. We can find no fault with the concept of improving the source plight of our research laboratories and institutes. The shift from finding of basic to applied research appears most important; however, this should not be at the expense of fundamental basic research. Accordingly, there would have to be the necessary growth level for the institute's budget.

-----See Page Two

Robert I. Levy, M.D. August 2, 1978 Page Two

The College is particularly concerned that the young perspective academician should be able to enter research without a financial penalty. We have long recognized the contributions of sincere, dedicated clinicians able also to perform clinical research in a superior fashion. The clinical investigators are research oriented practitioners and have made significant contributions, and will continue to do so in the future. Flexibility should be exhibited in developing combined clinical research training grants, program project grants, and supportive research in continuing education facilities.

Frequent examination of the need for research embracing the Bethesda-type conferences could lead to more vigorous research of both investigators and concepts. Finally, it was clearly evident in Secretary Califano's speech that he was for all that we are for; but he never did mention one word about increasing funding for these landable goals. Thus we have made our above recommendations.

Thank you for the privilege to comment and offer our concept and ideas at this time. We, of the College, would be most honored to be represented at any subsequent meetings so that we can have a continuing dialogue to develop a comprehensive, useful and efficient Five-Year Health Research Plan.

With best wishes.

Gordially,

Leonard S. Dreifus, M.D., F.A.C.C.

Leonard S. Decepted

President

LSD: j



THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

August 2, 1978

Secretary Joseph A. Califano, Jr. Department of Health, Education, and Welfare Washington, DC 20201

Dear Secretary Califano:

Responding to your recent memorandum requesting suggestions for health research support, I have enclosed a copy of the Maternal Health Policy approved in December, 1977 by the Executive Board of the American College of Obstetricians and Gynecologists.

Section II, Part B documents the general views of the College and those held by the Nurses Association of ACOG, which relate to health research. We will be pleased to provide more explicit suggestions if you wish.

Thank you for this invitation to comment. We will appreciate the opportunity to review the proposed principles which are developed for the October National Conference, and will be willing to provide additional resource information or names of individuals to work with you on any research project recommendations which concern our specialty.

Sincerely yours,

Warren H. Pearse, M.D., FACOG

Executive Director

Ruth Young, R.N., Director Nurses Association of ACOG

WHP, RY/ja

AMERICAN DENTAL HYSIENISTS' ASSOCIATION



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DISTRICT XII TRUSTEE
Lors T. Whitrord, R.D.H.
WASHINGTON OFFICE
Ben F. Miller, III
Suite 1006 1101 17th St. N.W. Washington, D.C. 20036 202-833-3024

August 3, 1978

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Secretary Joseph A. Califano, Jr. Department of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

The American Dental Hygienists' Association is pleased to have an opportunity to offer comments on the Department of Health, Education, and Welfare's plan to develop a multi-year strategy for support for health research acti-The allocation of dollars in order to finance basic and biomedical research represents a fundamental commitment by the Federal Government to the improvement of the health care delivery system. The American Dental Hygienists' Association shares a commitment to the delivery of quality health care in this country and, through our Education Foundation and its Committee on Research, has become involved in projects investigating preventive dental health measures, standards of dental hygiene practice, and the delivery of dental hygiene care in underserved areas.

The American Dental Hygienists' Association is interested in pursuing additional projects in health research and feels that the development of principles is an essential element of a comprehensive strategy to guide health research activities. We will be pleased to provide comments on the proposed principles and would like to receive a copy of them in draft form prior to the October conference.

Sincerely,

Jeannett S Buchanan, RDH Jeannette S. Buchanan, RDH President

Rodney S. Brutlag, CAE, Executive Director Ben F. Miller III, ADHA Washington Consultant

AMERICAN ENTERPRISE INSTITUTE



FOR PHOLIC POLICY RESEARCH
150 SEVENTEENTH STREET, N.W., WASHINGTON, D.C. 20036
11EFFONE 202 FEETERS 862-5856

CENTER FOR HEALTH POLICY RESEARCH Robert B. Helms, Director

August 3, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare HEW Washington, D.C. 20201

Subject: HEW Multi-Year Strategy for Support of Health Research

Dear Mr. Secretary:

We here at AEI applaud your efforts to devise principles to guide future federal support for health research. The purpose of this letter is to inform you of some of the people who have been involved in an AEI project to study these complex public policy issues.

In April of this year, AEI's Center for Health Policy Research assembled a group of medical and economic experts to consider the possibility of initiating a program of research dealing with public policy questions relating to the federal support of biomedical research. While we had an interesting discussion that day, one of our general conclusions was that there was very little good research that related directly to the kinds of difficult public policy choices which this country faces. We plan to publish the proceedings of this meeting later this year for the purpose of informing others of the complexity of these policy questions. We then plan to commission a small number of papers from thoughtful people which will attempt to more carefully delineate and identify important questions for future research. If we obtain some useful analyses of policy problems in biomedical research, we would present them at a future conference so that their contents may be discussed in depth.

I would urge you to seek comments from the people who attended the meeting and are listed on the attached sheet. All of these people are familiar with and have done some thinking about the issues involving federal support for health research. They would be able to contribute some useful suggestions about what kinds of policy questions are important and what kinds of research are required to shed light on these questions.

If we can be of further assistance, please let us know.

Sincerely,

R-3

Robert B. Hilms

cc: Karen Davis

American Federation for Clinical Research

President

Gerald F. DiBona, M.D.
University of lowa College of Medicine
lowa City, lowa

esident-Blect

William N. Kelley, M.D University of Michigan Medical School Ann Arbor, Michigan Secretary-Treasurer

Suzanne Oparil, M D
University of Alabama at Birmingham
Birmingham, Alabama

July 28, 1978

Mr. Joseph A. Califano, Jr.
The Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Secretary Califano:

Thank you very much for your letter of July 19, 1978. It was a privilege and an honor for the American Federation for Clinical Research to have you present your new program for the development of a new biomedical and health research strategy at our 1978 Annual meeting.

The Federation is vitally interested in the principles that would guide such a strategy. The Federation believes that a continuing committment to biomedical research is essential for the development of solutions to existing major health problems. Fundamental to this effort is the continued support of investigator - initiated grants in the basic and applied research areas. A vigorous program of high quality applied research on clinical problems is important but the highest priority should be given to the support of undifferentiated research in basic and clinical science.

It is evident that a strong program in biomedical and health research is critically dependent on sufficient numbers of highly trained biomedical scientists. The Federation believes that a renewed committment to the support of both pre-doctoral and post-doctoral training for research in the biomedical sciences is vitally important in this regard. Institutional training grants should be the principal means of assuring an adequate supply of biomedical research manpower.

The Federation is pleased to convey its views to you on this most important issue and would be pleased to participate further in the formulation of such principles in preparation for the National Conference of October 3-4, 1978.

Sincerely yours,

Gerald F. DiBona, M.D.

Merself. Di/Sona

GFD: kw

August 23, 1978

Dr. Donald Fredrickson, Director National Institutes of Health Bethesda, Maryland 20014

Re: HEW Multi-Year Strategy for Support for Health Research

Dear Dr. Fredrickson:

We are pleased at the opportunity afforded us by Secretary Califano, in this memorandum of July 19, 1978, to suggest the following principles for inclusion in the set of proposed principles to be presented to the National Conference on Health Research Principles, scheduled for October 3-4.

1. HEW research must give greater emphasis to the spectrum of clinical, social-psychological and technological needs associated with physical disability. This should include studies of the epidemiology of impairment and disability (measured as separate but related concepts), and studies of medical and social rehabilitation processes and outcomes.

The dramatic medical advances of recent years have resulted in increasing numbers of persons who might previously have died but now survive many years with lasting impairments. Persons with such impairments require medical attention, and often experience disabilities in carrying out a variety of tasks in their daily lives; the same persons generally have potential for productive and independent participation in society, given proper rehabilitation, technology, and opportunity.

Neither health research nor practice has kept pace with the growing number and types of impairments and disabilities, or with the potentials for rehabilitation. Note Secretary Califano's listing (p. 13 of his paper) "...all the health missions of HEW--prevention, delivery, regulation, standard-setting, and cost control ...", rehabilitation should be given explicit status.

- A. Research Needs Pertaining to Vision Impairment, Disability and Rehabilitation:
 - 1. research on eye care:
 - a) prevention
 - b) treatment
 - c) rehabilitation
 - 2. research in low vision
 - 3. research on diabetes and blindness
 - 4. research on the problems of aging that cause visual loss
 - 5. research on nutrition
 - 6. third party payments
 - 7. research on plans for national health insurance
 - 8. research on minority groups that have high incidences of visual losses due to economic factors.
- 2. HEW research should encourage collaborative research, not only of an interdisciplinary nature, but also interorganizational, especially to promote linkages between organizations with an applied health/social problem area focus and academic university departments. Scientific research

capability (including social as well as biomedical sciences) of "applied" non-academic organizations should be fostered through various mechanisms, including grants and contracts for research funding, internship experiences in such settings for graduate students in sciences, and so on.

The concern of HEW that basic research should be effectively linked to applied research, and eventually to action, can be furthered through involving organizations with an applied health/social problem emphasis in research directly.

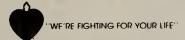
We look forward to participating in the National Conference. Sincerely,

R. L. A. Pla

Loyal E. Apple Executive Director

LEA: SC

American Heart Association



August 3, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Room 615F Hubert H. Humphrey Building 200 Independence Avenue, S.W. Washington, DC 20201

Dear Mr. Secretary:

The American Heart Association is most appreciative of the privilege of participation in the health research planning process you have initiated. As you know, the membership of our organization comprises a substantial number of research professionals, medical practitioners and non-medical business and professional volunteers. These groups are jointly committed to the support of a strong biomedical research capacity within the confines of the publicly contributed funds available to the American Heart Association. Consequently they also are of an accord in support for continued vigorous governmental support to insure the success of essential health research.

In this light, therefore, the American Heart Association urges that the first planning principle be that the proportion of the total health dollar invested in health research should be increased.

As you indicate in your letter, the Department of Health, Education and Welfare supports the largest health research establishment in the world. However, as you suggested in your address of April 29, 1978, that large establishment cannot accomplish several essential research missions. It therefore seems inappropriate to accept a postulate that because the investment is already large, it therefore has reached some theoretical limit. The only appropriate limit on expenses for basic biomedical research should depend on the limit of proposals for scientific study which are meritorious enough to promise a benefit to the health of the American public. Currently large numbers of such meritorious proposals are approved but unfunded. You noted in your address that the total spent for biomedical research is only 4% of the nation's health expenditures. Yet the establishment of a firm scientific knowledge base underlies all important disease prevention and real cost containment. Your address contains several specific references to these observations as in the cases of rheumatic heart disease, hypertension, rubella and polio vaccine. The logic of providing suitable support for the research to furnish that knowledge base as a primary planning principle is inescapable.

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August 3, 1978 The Honorable Joseph A. Califano, Jr. Page 2

The second principle recommended by the American Heart Association is <u>that</u> adequate support must be insured for basic biomedical research. The immediate corollaries to the principle are:

- 1. Provision must be made to upgrade research plant facilities which have been permitted to diminish to substandard levels.
- 2. Support must be provided to assure the training of the next generation of research scientists.
- 3. Primary emphasis must rest on investigator initiated proposals evaluted by careful and unhurried peer review. Long-term support for this category of research must account for inflation and a reasonable growth to allow for new proposals.

Both of the foregoing principles clearly are related to your suggested planning principles one and two.

Planning principle number three is <u>that all activities to be considered health care</u> research should be evaluated for scientific content and validity by <u>peer review or by the "technical consensus" process</u> (whichever is appropriate for the particular program).

The principle implies that large scale applications research must be proposed and mounted only on an assured base of fundamental knowledge and availability of sufficient well-trained investigators to perform the task. Many of the concerns connected with your call for more applied research would be mitigated if this principle became a part of the approved planning process.

Finally the fourth principle is that as priorities are determined for new categories of needed research and for costly field trials, money allocations should be provided for each newly defined responsibility. The mounting of substantial programs in "prevention, delivery, regulation, standards setting and cost control" could consume money in excess of the current NIH budget. Research expenditures should not be forced into the "rob Peter to pay Paul" circumstance by accepting the notion that in response to a newly perceived need, a vital and productive ongoing program must be curtailed.

These principles are strongly supported by the American Heart Association. We hope that they will be heard and discussed at your scheduled conference. We wish you all success in developing an appropriate long-range plan to provide needed stability and appropriate support for health research in this country.

Very truly yours,

W. Gerald Austen, M.D.

President

B-38 American Heart Association

President
PAUL E. TOTH
The Ford Motor Co
The American Road, WHO 297
Dearborn, MI 48121
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RALPH G SMITH, PH D The University of Michigan (313) 764 2594

Managing Director
WILLIAM E McCORMICK
475 Wolf Ledges Parkway
Akron, Ohio 44311
(216) 762 7294

July 31, 1978

Mr. Joseph A. Califano, Jr. Secretary Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

In response to your letter of July 19, 1978, on "HEW Multi-Year Strategy for Support for Health Research," we in the American Industrial Hygiene Association are very much interested and concerned regarding the continuation of health research in this country and appreciate the opportunity to comment on this vital issue.

The membership of AIHA is made up of approximately 4200 professionals whose major responsibilities are the recognition, evaluation, and control of those environmental factors or stresses, arising in or from the workplace, which may cause sickness, impaired health and well-being, or significant discomfort and inefficiency among workers or among the citizens of the community.

I have submitted your letter to the chairmen of our Bio-Medical Assessment for Job Placement, Bio-Hazards, Occupational Medicine, Workplace Environmental Exposure Levels, and Ergonomics Committees and asked them to solicit their committee members for health research suggestions. As soon as replies are submitted, I will forward them to you.

Sincerely,

Paul E. Toth
President - AIHA

PET/kb

President

PAUL E. TOTH The Ford Motor Co. The American Road, WHQ 297 Dearborn, MI 48121 (313) 322-0210

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ROBERT L. HARRIS, Jr., Ph. D. University of North Carolina (919) 968-4491

RICHARD B. KONZEN, Ph.D. Texas A&M University (713) 845-5531

WILLIAM H. KREBS, PH.D. General Motors Corp. (313) 556-1597

CHARLES R. McHENRY Xerox Corp. (716) 422-5751

CHARLES H. POWELL, Sc.D PPG industries (412) 434-3865

ALFREDO SALAZAR Palo Alto Medical Clinic (415) 321-4121

RALPH G. SMITH, PH.D. The University of Michigan (313) 764-2594

Managing Director WILLIAM E. McCORMICK 475 Wolf Ledges Parkway Akron, Ohio 44311 (216) 762-7294 September 1, 1978

Mr. Joseph A. Califano, Jr. Secretary Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

In response to your request for suggestions in the "HEW Multi-Year Strategy for Support for Health Research," I would like to submit these ideas:

- 1. There should be research conducted in determining maximum tolerable metabolic load. For example, some of the details that need to be considered in this regard are definition of exceeding the limits of homeostatic and other physiological defense mechanisms which may have adverse consequences from maximum metabolic load. One might also consider what other ways there are for determining a maximum value for a tolerable metabolic load under a set of defined conditions. Further, what about short-term peak exposures versus prolonged constant exposures.
- 2. More work is required to determine the mechanisms of infectious diseases in those industries such as meat packing, poultry, etc. For example, what is the mechanism and the potential protective measures that are best in situations where employes are potentially exposed to brucellosis. It appears that more information is required in this area of health concern.
- 3. More work is required to determine early indicators of neoplastic changes.
- 4. What sources are responsible for the hypersusceptibility reactions noted among the working population.

 Are they related only to work environment, or are the home and recreational pursuits significant contributing factors.

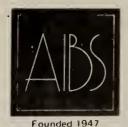
Secretary Joseph A. Califano, Jr. September 1, 1978
Page Two

These are part of a few of many issues that must be addressed with regard to the health and well-being of our working population. I hope that in the short time we had to review these issues we have been able to offer some questions of significance which will be addressed by your research advisors.

Sincerely,

Paul E. Toth
President - AIHA

PET/kb



AMERICAN INSTITUTE of BIOLOGICAL SCIENCES

1401 Wilson Boulevard / Arlington, Virginia 22209 Telephone: (703) 527-6776

9 August 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education and Welfare
Washington, D. C. 20201

Dear Mr. Secretary:

This is in reply to your letter of 19 July, requesting response to your projected multi-year support strategy. The development of a "strategy" for the support of research in mission agencies merits far more consideration than it usually receives. I shall not indulge in delineation of the political, self-serving and other variables which so far have defeated such efforts and which can be expected to hamper the implementation of your program. The views stated below derive from years of service on advisory committees and with the Office of Naval Research from which I retired as Director of Research.

Longer-term funding for certain elements in any major program has advantages but not without serious pitfalls. The same is true in terms of investment in investigators, some few of whom merit long-term support while the majority never deliver on the promise of the first year. Equally important are the factors which influence selection of those investigators for the longer-term support.

Although there might be implications for other elements as well, let us concentrate upon the NIH portion of HEW. NIH programs have suffered over the years from the vaciliation in congressional interest and intent. It represents a battleground for those who desire easy answers to the disease of the month vs. those who would sponsor basic research with no constraints upon the investigators and no accountability for program managers. Over the years, new hiring represented this vaciliation and, today, there are staff members who believe in one or the other approach and daily fight the battle to that end. Inevitably, they are joined by the members of congress and their staff on

one hand and the private investigator and university administrators on the other, each seeking to realize objectives through the medium of the agency, its staff and divided loyalties. The first point is that NIH is neither solely the supporter of basic research in biomedicine nor solely a mission-oriented agency in health delivery. It should be the optimum mix with all of the advantages accruing from internal clinical and research capabilities combined with external support through individual grants and centers. The elements referred to above are based upon functions and relationships to the ultimate clinical evaluation and application on disease entities. Your multi-year strategy must show how long-term support of parts of each element will be most productive for the science involved as well as the applications to health. Of course, this requires appropriately communicating its efficiency and rationale to the public.

Individuals will be carefully selected for longer term support on the basis of their promise in an area of expertise as well as their contribution to the next level which will address a function or some other larger aggregate. Hence, while those reviewing proposals must concern themselves with individual competence, they also must consider the larger picture which necessarily includes adaptability of the investigator. We have not done well The investigator who truly learns more and more about less and less for over twenty years has enjoyed support to the exclusion of those who must be found and stimulated to play the next role of putting some of the pieces together. Selection of candidates for longer support, then, means more careful review of proposals and orientation of the investigators. This starts our process with review or peer panels, many of which are composed solely of those individuals who have spent their professional years constraining their field rather than extending its relationships or contexts. Certainly, competent investigators are quite aware of their peers who are capable of seeing the bigger picture, of asking "so what?" of reported data and ascertaining potential applications. Peer review groups must have some membership from this section of the research community to assure an appropriate level of support of those you must find. Further, it is essential that the review groups be oriented to the Institute's total program and objectives. Over the years, there have been unnecessary confrontations between review groups and program managers where there should have been an enthusiastic spirit of mutual problem solving. The relative roles were ill-defined or evolved through a struggle for control. Hence, the program as represented to the review group by the program manager should be the focal point for the related evaluations. He must be thoroughly knowledgeable of the subject, have a sound rationale and wellfounded conclusions supporting his contention that a particular program is the preferred one for achieving the desired results. The extent to which he receives help from others in his Institute for structuring that program and shares such program development with his review group or individual members of that group will determine and enforce the program manager's controlling role.

Experience shows that regardless of his own previous history or credentials in research, those still active in academic research, in particular, employ mechanisms which deprecate his efforts. Thus, your "strategy" must on one hand reinforce the preeminence of the program and, on the other, sustain and foster the responsibility of program managers to maintain that focus. In return, you will gain in quality of program management and the emergence of a team approach in lieu of a relatively perfunctory allocation of funds to support research and researchers. Further selectivity and reduction of redundancy can accrue from judicious use of the Science Information Exchange (SIE) reports on research currently supported elsewhere and the Biosciences Information Service of Biological Abstracts (BIOSIS) abstracts of presently reported research findings. Any review group, armed with this type of information across the spectrum under consideration, can employ NIH funds to fill the holes, consolidate data and accelerate the solution of problems.

Since all of your present basic researchers cannot be supported by funds available, the selection of those for support require some "phasing in" consistent with the same inevitable funding constraint. The question then becomes what percentage of investigators should continue on annual renewals following annual appraisals of progress. This appraisal process is the next area demanding attention. Far more effort and emphasis have been upon dispensing funds than on accounting for those provided in a previous year. Peers are far more motivated to obtain funds for their discipline than they are to be critical of their colleague's efforts. The resultant flow of one-year investigators will allow sampling of younger participants as well as more novel or innovative approaches. The program will remain healthy only so long as a significant percentage of the effort can be turned over and/or off. NIH has extensive experience in problems associated with turning off certain of its research which has enjoyed some tenure. Investigators and their universities begin to build staff and plan around the grant and, as time goes by, come to "expect" renewal. The greater the amount of funds involved, the longer the support, the broader the spreading of tentacles, the more difficult it is to terminate without too frequent pressure from upper echelons on campus and appropriate members of congress. (Indeed, some of the most grateful investigators you will know are those who wanted one or two years to accomplish a given task, establish an hypothesis or explore a lead. They appreciate the pleasure of completion and do not establish a perpetual requirement for support of an endless pursuit.) In the meantime, there will be a change in staffing at NIH due to the reduced requirement for processors of proposals and increased emphasis upon appraisal. Too, there must be provision for terminating long-term grants as this transient population moves elsewhere or into administrative positions. Similar complications arise in equipment relocation.

Much the same consideration of individuals and performance of tasks is necessary at other levels in the system. Program managers vary tremendously in capability to assess their area and its researchers well enough to structure the best mix for support of short and long-term investigations. Here lies the key to NIH operations - the programming of research versus the supporting of research, to understand a function, the organization of biological data, the delineation of a system, that pertain to states of health. Your "strategy" will have an ingredient for this programming function because there are these objectives other than mere training and research support.

On the grander scale, NIH must have some strategy for weighting and establishing priorities among the worlds of therapy, prevention and maintenance. Characteristically, medicine has progressed through treatment of symptoms, to understanding an illness and its therapy to, hopefully, appreciating the daily bodily maintenance and prevention. What percentage of funding should be devoted to each of these aspects? For how long? Suppose we just wrote off the presently afflicted and devoted funds to prevention to assure that no future generation would have the same? Certainly, that sounds heartless but we do make those decisions today in the allocation of funds and we make them in a far more cruel way as we wax and wane in our responsibilities in recurrent feelings of obligation or emotional prodding by others. strategy you devise should deal with this problem on some other basis even as should the allocation between therapies, afflictions, or preventive programs. Of some concern in this allocation process is the balance of basic research vs. applied, already mentioned. This is due to the fact that therapy is closer to applied and, as we know from experience, applied is the more expensive aspect. On the other hand, to build the information base required for adequate coverage of all factors in prevention necessitates a broad basic research program. The relative costs, then, of therapy vs. prevention include the support of appropriate research. Such comparisons are difficult if not unfair to attempt because applied research, by its very nature, is limited in pay-off on a specific target while basic research has value through its unlimited potential for multiple applications. Unfortunately, it is easier for the public to understand the therapy emphasis and its related research because they have that promise of pay-off. Further, the Institutes "look" as if they are doing something about health. Thus, major effort or emphasis upon basic research demands educational programs for the public, something which we have not yet performed well.

Let us consider another part of your "strategy" which will rise or fall on public participation-health services. The capability of the public to understand what you are doing becomes reflected in its support, its participation and, when necessary, its compliance or conformance. The critical test of your strategy will be the extent to which the public modifies its living style towards a healthier mode. When more of the American public acknowledges that it stopped smoking, reduced its caloric intake,

increased its exercising, paid more attention to labels and directions on prescriptions, et cetera because of research results reported from NIH programs, your struggles will be lessened immeasurably. What balance of effort should be devoted to this program of informing, convincing and verifying over time? I note no consideration of this aspect of delivery, assurance of information receipt and action, in your address or letter. Thus, it is insufficient to just represent the problems associated with underwriting an entire year's program for a five-vear period on one year's budget. It is important in obtaining funding from Congress and the public that your "strategy" contain measures beyond the mere supporting of research, long-term or short. It must include evidence of improved stewardship, programming and implementation.

Trying to cost out some funding from the clinical center or an individual investigator, even when cloaked with the prestige of international recognition, does not ring true. Claiming credit for the extensive training programs and parading the researchers who had to be supported to assure "preeminence in medicine" will have to fade into the background in your new strategy. should be the most objective effort to treat real problems and derive the best solutions associated with your stated goal -- "to guide health research activities in the Department and in the Nation in years ahead." There are many goals which have been used over the years in the establishment and the continued supporting of NIH. Not many of them have been realized. At this juncture, the American public supports NIH for anticipated improvement in its health, collectively. The treatment of rare disorders, the development of expensive electronic supplements to human function and the exorbitant medical costs of daily care do not hit the mark.

Other things will assume their proper order once the audience understands and appreciates your request for assistance in developing a strategy, aimed at considered, prudent expenditures of limited funds and utilization of the best research potential in behalf of the public's health. Your number one priority, then, is dispelling public skepticism of this being another quise for requesting more of the same; that it truly is a search for improved quality of research and assured utilization of results in the public sector at the same time the Institutes reduce staff and undertake programming based upon longer range support of research demonstrably of greater quality and more relevance to NIH objectives.

I would like to receive your forthcoming report and be apprised of your progress towards achieving your goal. Further, I would be pleased to play whatever role I can in supporting you in its achievement.

Richard Trumbull Executive Director



AMERICAN MEDICAL ASSICIATION

535 NORTH DEARBORN STREET • CHICAGO, IILINOIS 60610 4 (312) 751 6000 • TWX 910 221 0300

JAMES H SAMMONS, M D Executive Vice President (751 6200)

August 4, 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education and Welfare Washington, D. C. 20201

Dear Joe:

I am pleased to respond to your letter of July 19, 1978, in behalf of the American Medical Association.

The efforts of the United States in health research and the future of Federal support of such research are of the utmost importance to the future of the people of the United States and, indeed, to the world. The American Medical Association is aware of and concerned about the use of finite and, in some instances, scarce resources in the United States for the almost infinite number of human and social purposes on which we are embarked.

It was the recognition of limitation of resources and the necessity to use them wisely and well in behalf of all members of our society which caused the American Medical Association to appoint a National Commission on the Cost of Medical Care, to devote time and resources to its efforts and to give the most serious attention to the Commissions' recommendations. The cooperative efforts to contain the costs of medical care which the American Medical Association, the American Hospital Association and the Federation of American Hospitals have undertaken clearly indicate our commitment to make the most effective use of limited resources.

The report of the National Commission on the Cost of Medical Care has a recommendation, adopted by the House of Delegates of the American Medical Association in June, 1978, that: "There should be increased funding for research toward basic scientific understanding of disease mechanisms." This recommendation was adopted as was a resolution stating:

"Resolved, that the American Medical Association advise Congress as to the insufficient support being directed toward basic research in comparison with other health related projects, and urge that added consideration and financial support be directed toward the correction of this inequity."

There can be no question of the timeliness and significance of a comprehensive review of Federal support for basic research in the field of health. The issues which must be addressed are both immediate and long term, are of great complexity and have major implications for the use of current resources, future commitments of scientists, institutions and public and private resources and their effects on health and welfare. Our comments are by no means exhaustive and are organized according to the various components of biomedical research and their applications. We would be glad to elaborate on them at the conference which you are convening at the National Institutes of Health on October 3-4, 1978 and in further statements which might be developed subsequently.

Fundamental Biomedical Research

The great gains of the late nineteenth and twentieth centuries in the prevention of disease, the amelioration, cure and rehabilitation of persons who suffer from disease, are based on the fundamental scientific research which has been carried out using public and private resources to conduct them. The scientific efforts conducted by the U.S. Public Health Service, particularly through the National Institutes of Health, have been instrumental not only in providing essential new knowledge and technology but also in stimulating and providing support for research conducted throughout the world.

The intramural research conducted by able scientists and their colleagues at the National Institutes of Health, other components of the U.S. Public Health Service and the Food and Drug Administration, for example, has served the public well. The Federal Government should maintain and strengthen its own fundamental research activities because federal agencies can address certain fundamental biomedical questions more effectively than other organizations and institutions. This has been amply demonstrated over many years. Therefore, it is imperative to continue to use resources of the Federal Government to conduct fundamental biomedical research within agencies of government.

In supporting fundamental research of able scientists and institutions which are not within the Federal Government, it is essential that DHEW have excellent scientists within it to advise on matters of extramural fundamental research which receives Federal support as well as to continue to use advisory and review bodies composed of non-governmental scientists. Since good scientists can be attracted and retained only if they are conducting their own research and advancing knowledge through their participation "at the bench", adequate support of Federal intramural fundamental research should be assured in any long-range plans of the Department. It is our view that the Federal Government should continue to allocate resources to intramural research programs within DHEW to assure their continuity and excellence.

It is also our view that scientists working in non-governmental laboratories and institutions are essential contributors to fundamental scientific knowledge and that the Federal Government should continue to invest substantially in the

development of new knowledge and technology through the support of extramural fundamental biomedical research. Since the very nature of biological phenomena is evolutionary and complex, advances in scientific knowledge are long-term, derived from the ideas of imaginative and able scientists who need sustained support over many years. At the same time, resources must be sufficient to allow younger scientists with new ideas and approaches to undertake careers in fundamental research with the expectation that they will receive support for their scientific contributions.

Research Capabilities - Present and Future

Over many years and from many sources the United States has developed research capabilities unequalled in the world. Its capabilities in the sciences fundamental to health and medicine remain high, although some observers believe that they have declined in the past few years because of increasing demands for the limited resources of people, material and funds. The desire to have immediate solutions to all problems, the impatience with the time required to prove scientific hypotheses which when proven and applied do not solve all human ills, the non-intellectual anti-"elite" mood of many persons threaten the continuing short-term and long-term public investment in fundamental research in the United States and in other scientifically and economically advanced nations. These threats are serious and must not be allowed to erode or eliminate investment in future improvements in health and in the welfare of people in our society. The Federal Government has a major responsibility in reversing current trends as do scientists and persons in the health professions and the institutions and organizations in which they serve.

Scientific research has its origins in the ideas of persons who are well prepared in the field and who can observe, create hypotheses and test them. The future depends on investment of resources in providing education and research experience for able young scientists and in having funds available to support them when they undertake careers as research scientists. In recent years the availability of funds for research training and support of new scientific endeavors has declined. It is our opinion that the Federal Government should increase its current investment in young scientists, in their training and in their initial research. A portion of available resources should be preserved for these purposes even though Federal funding of application of new knowledge and technology through demonstration projects may have to be limited. If opportunity to develop new scientists and their ideas is diminished or lost there will be a rapid decline in the capability of the United States in fundamental research related to health.

The fundamental biological, chemical and medical problems which face us require complex equipment and facilities, capable scientists and technologists and time for their elucidation and solution. Therefore, resources must also be made available for facilities and equipment which will enable scientists and others to explore the unknown. In a sense this is "risk capital" which should be expended wisely but which must be available if scientific advances are to

continue. It is clearly incumbent on scientists, institutions and organizations to use expensive resources effectively. It is also essential that the granting of Federal funds foster cooperation, sharing and full use of all resources brought to bear on the pressing problems of biology, health and disease which await investigation and possible solution.

Applications of New Knowledge and Technology

New knowledge and technology which have proven their scientific merit must be applied at the earliest date compatible with safety, availability of persons capable of applying the knowledge and technology and the facilities and equipment necessary for their application. In many ways this particular aspect of the issues surrounding research presents the greatest dilemmas. Applications of new knowledge and technologies are always expensive. There are great pressures to divert resources from their development to the application. This is particularly true of the pressures on scientists and technologists who may be required to exert their efforts in practical application, which they may or may not be suited to, and to diminish their efforts in fundamental scientific research.

Support for the application of proven new knowledge and technologies in health and medicine is available from multiple sources. Although the Federal Government has responsibility and interest in making application possible, this responsibility and interest is most effective when multiple public and private resources are used. The Federal Government can encourage and foster cooperative efforts among all groups who have resources to bring to bear on problems of health and illness and should do so. It cannot and should not be the sole or even principal resource for the use of medical and other scientific knowledge and technology in improving the health and well-being of individual citizens. The Federal role is more significant and useful in using its limited discretionary resources in supporting fundamental research.

Synthesis and Coordination of Science and Technology

Because of the diversity of knowledge, technical skills and interests of individuals, of scientists, institutions, local communities, states and the nation it is inevitable that different emphases will exist in the pursuit of new knowledge and its eventual application. This diversity has led inevitably to specialization of individuals and institutions and has been the great strength of science and technology in the United States. With the need to conserve resources there is also need to synthesize knowledge and technology and encourage coordination of efforts in biomedical and other scientific research. At the same time individuals and the organizations and institutions in which they work should pursue those areas of investigation in which their capabilities and interests lie. All components of the biomedical enterprise should be identifying gaps in knowledge, areas which can be effectively pursued, and sharing new knowledge as it is gained. Coordination, to be effective, must first occur in the community of scientists and in their institutions and organizations. It cannot be done by

the Federal Government in the absence of coordinated and cooperative efforts among scientists themselves. Legislative authorities for research, policies of Federal and of the public and private agencies should foster coordination and cooperation. Special narrowly categorical legislation and funding policies tend to limit coordination and in some cases make it virtually impossible in local settings.

As a general principle legislation and funding policies should be as broad as they can be while assuming reasonable accountability on the part of those using the Nation's limited resources. This is particularly true of the support of fundamental research, wherever that support may be generated. Flexibility is essential in the provision of resources if serendipity is to be useful (as it must be in exploring new ideas and testing new hypotheses). Non-governmental bodies should have ample opportunity to present information and evidence in the formation of public policy and research efforts. Governmental agencies have a responsibility to coordinate their efforts and policies if resources are to be well and effectively used. This is an obligation of the highest order for all who are using resources to pursue scientific knowledge and technology and to apply this knowledge and the technologies derived from them to improve health and to prevent or contain illness.

May I again express my pleasure in being asked to submit views and suggestions on Federal funding for health research. We look forward to continuing opportunities to participate in the comprehensive review of Federal support of health research which you have undertaken, a review which is timely, wise and of the greatest importance for all.

incerely,

H. Sammons, M.D.

AMERICAN NARCOLEPSY ASSOCIATION

P. O. BOX 5846 • STANFORD, CA 94305

OFFICERS

William P. Baird, President

George E. Schattle, Vice President

August 10, 1978

William C. Dement, M.D.
Elliott D. Weitzman, M.D.
Richard J. Wyatt, M.D.
Vincent P. Zarcone, M.D.

MEDICAL CONSULTANTS

Sheryll Sue Carella, Secretary/Treasurer

The Honorable Joseph A. Califano, Jr. Secretary of The Department of Health, Education and Welfare Washington, D.C. 20201

Re: HEW Multi-Year Strategy for Support for Health Research

Dear Mr. Califano:

Thank you for this opportunity to submit our suggestions about principles upon which to base a strategy for the allocation of resources among federally supported health research programs.

More than one-quarter of a million Americans are afflicted with narcolepsy. It is a serious illness, and as with most organizations concerned with specific disorders, we believe our concerns (narcolepsy, sleep apnea and chronic sleep disorders) are not receiving the research attention which is needed and deserved. Often the efforts of voluntary health organizations seem pitted against one another as each seeks to obtain a share of the funds available for research. Sometimes this results in the funding of research projects with little or no relationship to research opportunities, investigators' interests or the relative significance of the health problems being addressed.

We do not believe it is a callous lack of concern for the needs of others which sometimes results in disease-of-the-month groups demanding special attention, rather such efforts are the result of frustration with the existing system which fails to give fair consideration to the needs of all and allocate research resources accordingly. We recognize, and we believe that most voluntary health organizations also recognize, that pursuit of narrow self-interest within the present system is often counter-productive; however, we believe such advocacy will not only continue but will increase until the fundamental access of past inequities are recognized and eliminated.

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Some of the basic causes, we believe, are inherent in the existing structure. They are part of the divisions and delegations of responsibilities which have been made and, in part, result from the factors which are considered and the processes used in reaching research support decisions. Restating the same arguments which have been offered in the past about the wisdom on which allocation decisions have been based will not make these arguments more convincing, productive or valid.

Identifying principles upon which a more equitable division of research resources can be based is, we agree, an important first step in resolving the unproductive conflicts and unifying the strengths of those concerned with health related problems in this country. To this end, we suggest the following:

The objectives of providing federal support for health related research projects should be specified.

There should be clear statements about what we want to accomplish. The statements should include factors which can be quantified so that competing needs will have a uniform basis for comparison. For example, we suggest our two major concerns should be for improving the quality of life and reducing the economic costs associated with health problems.

The priorities for health related research projects should be established.

Given clear objectives which enable competing needs to be quantified, our priorities for dealing with identifiable disorders should be established and made public. The priorities should be clear and arrived at through a uniform process which deals fairly with all health problems. The process used and criteria upon which priority determinations are based should be explained. There should be provision for constructively challenging these priorities and changing them where evidence warrants with minimum distortion to the overall system.

The probable results of all proposed research projects should be estimated in quantitative terms.

We are aware of assertions by respected authorities that the greatest benefits come from support of basic scientific research as opposed to research which relates to specific disorders. However, such claims seem based only on anecdotal evidence. These assertions should be quantified and subjected to rigorous scientific evaluation. There is no area of medicine in which anecdotal evidence is accepted as a valid basis for making decisions.

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There are probably more investigators interested in conducting basic scientific research than there are concerned with research relating to any one specific disorder; however, loud voices and large numbers may make a publically persuasive argument, but not necessarily one which is valid.

Most important, arguments about the merits of basic vs. targeted research tend to obscure the more fundamental issue: the need to evaluate each individual proposal (basic or targeted) in terms of cost and probable results.

Research funding decisions should be based upon probable research results measured against National research priorities.

This is probably the most crucial issue and the area of greatest concern. We do not believe the present system results in a sufficiently close relationship between the projects which are funded and the health needs of this country.

Another step should be added to the evaluation process. This step would provide for the review of all research proposals and measurement of the probable results of each in relation to National health priorities. The results of this review should have a strong influence on research funding decisions. Of course, scientific merit must be considered. We do not want to see bad research funded simply because it addresses an important priority, but neither do we wish to continue funding the best of research proposals (ranked according to scientific merit) which are unrelated to our health needs. The review process we are suggesting should be conducted by a single entity evaluating all proposals relative to the same criteria. The entity should be independent of individual Institutes or other HEW components.

Consumers who suffer from health problems should participate in the decisions about objectives, priorities and the funding of health related projects.

Consumer selected research investigators who are authorities on the research needs relating to specific disorders should be called upon to identify existing research opportunities which have a high probability of producing worthwhile results without the need for further basic scientific research progress as well as to identify the areas in which basic scientific research is likely to produce results beneficial to the respective disorder. All identifiable disorders should have an opportunity to participate in this process, not just a select few.

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The general public may respond to emotional appeals for disease targeted research but the individuals who have these disorders want results and not necessarily the conduct of a specific kind of research. If medical authorities whom the consumers respect advise that basic research is needed before progress is likely (relative to the specific illness with which they are concerned), the consumer will support funding for that research.

There should be opportunities for those afflicted with specific disorders to identify problems associated with each disorder. Improvements in the quality of life of an afflicted person might be achieved without an improvement in health. For example, is there any wisdom in withholding pain killing medication from a person who is dying and enduring great suffering? If the only reason for withholding an ample supply of pain killing medication is a law which is intended to prevent drug abuse then that law could be modified to permit the use of medication where no demonstrated risk of or contribution to abuse is involved. Consider the needs of a person who is afflicted with a chronic, life-long illness for which medication (classified as a dangerous drug) must be taken every day for the rest of their life. If there is no sound medical reason for seeing the patient, the physician should be able to provide an ample supply of that medication to meet the patient's needs until such time as the patient should again be seen for medical reasons. Those afflicted with narcolepsy are often required, at considerable hardship in some cases, to go to their doctor's office once every month in order to obtain a new prescription for the medication which they must take. A low cost change in the law might dramatically improve the quality of life for such individuals and reduce the overall cost of medical care. Projects investigating problems such as the above examples should be valid uses of research funds.

Convincing communications of a fair and rational basis for research funding decisions are essential.

Not only must decisions be made on a rational basis but an understanding of that basis and convincing evidence that it has been uniformly applied must be communicated to concerned individuals and organizations.

An observer, selected by and reporting to concerned voluntary health organizations, should be present during deliberations involved in reaching decisions regarding the funding of research proposals. We believe this would greatly increase consumer confidence in the processes. These observers would not be a part of the evaluation process. They would only be responsible for observing and reporting to the voluntary health organizations that the evaluation process gave fair and equal consideration to the merits and priorities of all proposals.

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Research investigators are a valuable research resource.

The time, energies, interests and talents of our research investigators constitute one of this nation's most valuable resources. Too often the talents of our research investigators are utilized inefficiently by forcing them to become authorities on "grantsmanship" in order to secure funding for their projects. A minimum of the investigator's time should be required in order to draft and assure that their proposal receives a fair hearing. Their time could be better spent doing research.

The burden of applying for project continuation funding and accounting for expenditures of research funds should be kept to a minimum. It is sometimes less expensive to accept unwise and inappropriate spending within a research project than it is to guard against such waste. Honest mistakes are acceptable. Some waste of funds is expected. Guarding against waste can become the most significant waste of all.

Recognizing investigators as a research resource and affirming the need to simplify procedures to conserve their time suggests the possible value of a service within HEW which could assist researchers in complying with both the formal and informal requirements and procedures of the various components of HEW. Perhaps such a service should be offered by the Division of Research Resources.

Funded projects should be assured of adequate funds and sufficient time so that the natural progress of a research project will produce measurable results before funds and time run out. Research does not know we have a calendar.

Lastly, the participation of all competent research investigators (young and old) should be encouraged by providing opportunities for individual achievement and recognition. Cooperation rather than competition between investigators should be encouraged.

The suggestions contained in this letter have not yet been reviewed by our Board of Medical Advisors. Your letter of July 19, has been forwarded to them as well as to several other authorities whose opinions we respect. Our views may change as a result of their recommendations.

The Honorable Joseph A. Califano, Jr. August 10, 1978
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Please send a copy of the proposed principles and any interim communications on this subject to:

The American Narcolepsy Association c/o Sheryll Sue Carella 524 Skiff Circle Redwood City, California 94065

Sincerely yours,

William P. Baird, President

American Narcolepsy Association

Sheryll Sue Carella, Secretary American Narcolepsy Association

WPB:SSC:jf



University of Arkansas for Medical Sciences

Department of Anatomy Slot 510 4301 W Markham Little Rock, Arkansas 72201 August 21, 1978

Joseph A. Califano, Jr. Secretary of Health, Education and Welfare 330 Independence Ave. S W Washington, D. C. 20201

Dear Dr. Califano:

I have been requested to comment on the needs for research on Narcolepsy with respect to the HEW Multi-Year strategy for support of health research by Mr. William P. Baird, President of American Narcolepsy Association. Narcolepsy is a disease which adversely affects the life of many thousands of our citizens. Estimates range between 300,000 and 500,000 nationwide. Past research efforts have been meager and primarily aimed at documenting the nature of the disease. Sufficient progress has been made in this area to warrant support of basic research with the intent of providing effective treatment of the disease. Currently, clinical practise is geared more toward helping the patient adjust to his condition.

There is no cure for narcolepsy and treatment is often unsatisfactory. I would strongly urge consideration of support for basic research in this area. Affected dogs have been found with symptoms similar to those of humans. These animals provide a unique opportunity to study this disease.

Sincerely yours,

Edgar A. Lucas Co Director Sleep Clinic

University of Arkansas for

Medical Sciences

cc: William P. Baird



THE AMERICAN NATIONAL REDUCTOSS

NATIONAL HEADQUARTERS
WASHINGTON, D. C. 20006

OFFICE OF THE PRESIDENT

August 4, 1978

Dear Mr. Secretary:

I appreciate your affording me the opportunity to comment on the future of Federal support for health research. The American Red Cross has a deep commitment to improving the health of the American people and we have long enjoyed an excellent relationship with the Department of Health, Education, and Welfare in a variety of cooperative endeavors to that end.

I commend you for your intent to develop a five-year strategy for funding of health research. The Red Cross has received funding for a number of projects from the National Institutes of Health, particularly in relation to blood. Our experience in the uncertainty of short-term funding convinces us that longer term planning would be a positive forward move. I have been concerned over the inadequate funding for blood resources as evidenced in the diminished financial support of the American Blood Commission as well as inadequate funds to support approved programs in the blood resource area. I consider the nation's blood supply to be a critical component of the overall health area and one which requires a long-term commitment of support, especially from the government sector.

With regard to the principles underlining a five-year plan that you enunciated in San Francisco on April 29, 1978, I am in full agreement.

I wish to comment specifically on a subject which is referred to from time to time in your April 29 address, namely, support for fundamental research in the behavioral sciences.

It is widely known that major changes in national health statistics would occur if men and women followed simple, well-known rules with respect to maintaining current immunization and nutrition, exercise, and the avoidance of excessive use of alcohol, drugs and tobacco. The self-help concept should also include an understanding of basic accident prevention, knowing how to cope with emergencies, and caring for the sick, elderly and handicapped at home rather than in institutions.

These topics--and many others--are covered in the broad range of American Red Cross educational services, as well as in the freely-available services of other voluntary organizations and public bodies. A grave national problem is the unwillingness of large numbers of people to avail themselves of these life-saving and health-sustaining services; hence, we come to a basic question in behavioral science: "What does it take to persuade a presumably intelligent and normal American to take elementary steps on behalf of himself or herself and his or her family to preserve health?"

I am not in a position to estimate the cost of research in behavioral science to seek an answer to this question, but I am confident that it would be a pittance in contrast to the staggering costs we pay for illnesses and accidents caused by indifference, neglect and carelessness. I urge consideration of a joint Federal-Red Cross research project in this field. I am confident that it would receive enthusiastic support of our chapters and that substantial numbers of volunteers—of all ages and socio-economic backgrounds—would wish to be involved. It would be fully compatible with the purposes and principles you have set forth, and I shall be pleased to discuss this further with your designee.

The American Red Cross will appreciate receiving a copy of the proposed principles to be discussed at the October 3 and 4 meeting, and I look forward to the opportunity of attending that conference.

Singerely yours,

George M. Elsey

The Honorable
Joseph A. Califano, Jr.
Secretary of Health, Education,
and Welfare
Department of Health, Education,
and Welfare
Washington, DC 20201

cc: Dr. Frank Stanton

American Nurses' Association, Inc.

2420 Pershing Road, Kansas City, Missouri 64108

(816) 474-5720

Barbara L. Nichols, M.S., R.N. President

Myrtle K. Aydelotte, Ph.D., R.N., F.A.A.N.

Executive Director



Washington Office: 1030 15th Street, N.W. Washington, D.C. 20005 (202) 296-8010

August 4, 1978

Dr. Donald S. Frederickson Director, National Institutes of Health Department of Health, Educaton and Welfare Building 1, Room 124 9000 Rockville Pike Bethesda, Maryland 20014

Dear Dr. Frederickson:

This letter is in response to Secretary Califano's request of July 24, 1978, regarding the development of health research principles.

The American Nurses' Association supports the five principles proposed by Secretary Califano at the annual meeting of the American Federation for Clinical Research and the five-year research planning. We suggest short-range and long-range planning principles. Short-range principles should include:

- a clear statement of the philosophy, goal, and objectives of the fiveyear plan with emphasis on definitions of health, consumer rights, care, and research terminology;
- 2. incorporation of interdisciplinary theory and practice for a clear understanding of research on prevention of illness and research on clinical treatment and rehabilitation;
- compilation of materials to identify the number of researchers in all health disciplines, e.g. pharmaceutical, medical, nursing, dental, etc., that would distinguish areas of needed research manpower and resources;
- 4. investigation into research content areas, both in the basic and applied research fields, that would identify areas of omission and/or the need for replication studies, e.g. life satisfaction of the elderly, the relationship of stress and illness;
- 5. evaluation of the cost and effectiveness of present health care delivery systems and the care process;

- 6. investigation of the major health problems affecting the productivity and life of the American people and the economic, psychological, and sociological cost of these major health problems;
- 7. research on methods for improving the theory, design, sampling, measurement, and statistical analyses of research for maximum validity and reliability;
- 8. development of criteria to review proposals that would evaluate the quality and the direct or indirect contribution of the research to the health of the American people;
- 9. comparative historical and current studies of the utilization of research findings in practice of various health disciplines.

From findings of these nine suggestions, priorities could be established based on need. These priorities would determine the major types and areas of health research and their proportionate funding (research, manpower, resources) consistent with the planning goal and objectives.

Long-range research efforts could be directed to research on established priorities from the short-range plan. In addition to the research on the priorities, long-range principles should include:

- the cost and effectiveness of duplicated technological and health manpower effort;
- 2. the cost and effectiveness of new methods of health care delivery systems;
- 3. alternative methods for the dissemination of research findings for greater utilization in practice;
- 4. the interaction and compliance of patients with various mixes of health care providers;
- 5. consumer satisfaction with health care delivery systems and health care providers;
- 6. the timing and effectiveness of health education.

The director of the Department of Research, Grants and Contracts of the American Nurses' Association requests that she and representatives from the ANA Commission on Nursing Research be included in future meetings and communications on this most important research dilemma. We would especially like to attend the National Conference scheduled for October 3-4, 1978.

Sincerely,

COMMISSION ON NURSING RESEARCH

Barbara Hansen

Barbara Hansen, Ph.D., R.N., F.A.A.N., Chairperson Juanita Fleming, Ph.D., R.N., F.A.A.N.
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BH:PB:pac

Enclosures: American Academy

American Academy of Nursing List Commission on Nursing Research List



American Osteopathic Association

September 1, 1978

The Honorable Joseph A. Califano, Jr. Secretary
Department of Health, Education
and Welfare
Washington, D.C. 20201

Dear Mr. Califano:

The American Osteopathic Association is pleased that the President, through you, has sought to review the federal commitment to health research and to developing a long-range plan. It is obvious, I am sure to you, that no single response would be adequate for the issues raised in your letter of July 19, 1978 and in your speech to the American Federation of Medical Research.

Certainly the requested comments and the interchange which will occur at the upcoming National Conference on Health Research Principles will give additional opportunity for dialogue and review this most important undertaking. I cannot too strongly emphasize this Association's appreciation for the need to develop a long-term federal strategy and concomitant commitment to consistent funding for the next five years.

The following are only a few of the more significant issues that we feel deserve consideration in planning this strategy:

SUPPORT - Not only should the support for fundamental research continue but it should take into consideration equipment and facility needs () ot only development and maintenance of current equipment and facilities but the planning for new institutions and their needs.

The program under the Biomedical Research Development grant is a good example of the type of program which could be further expanded in \Re s support in order to achieve this goal and consider also the needs of the young institution and investigator as outlined below.

The support level should be stable so that the optimum utilization of research personnel and facilities will occur. Peaks and valleys of support are harmful to the entire research effort. They chill institutional involvement due to the eifficulty of planning on a roller coaster of support.

Reexamination of the decline of direct funds into research activity and the increase in the amount spent in indirect costs in institutional support is needed. We recognize that institutional overhead is climbing and the

The Honorable Joseph A. Califano September 1, 1978 Page 2

institutional financial director is obligated to seek a balance of his overhead in all possible areas. The realization of this and the formulas used to supply indirect cost over direct costs grants needs to be reexamined.

YOUNG SQUIRTS - Your concern for the young investigator and with him the young institution is of special interest to us. In the past decade we added nine new colleges of osteopathic medicine bringing our total to fourteen. These institutions, primarily involved in the training of primary care physicians, need the cultivation to develop research potential not only in basic biomedical sciences and in the traditional research in curative medicine, but there is a need to continue the advances that have been made in the areas of preventive medicine and in health care delivery systems. We believe that we have unique opportunities because of our large base and experience in the production and supply of primary care to the citizens of this country to participate in meaningful work in this area. The federal philosophy needs to supply the special nurturing of these early sprouts to insure that they will flourish and contribute their potential.

INTERDISCIPLINARY ACTIVITY - Interdisciplinary action and dialogue has already been of concern to this profession, and through its Bureau of Research we sponsor an annual Research Conference for both clinicians and basic scientists to get together and review their activities and direction. The continued intercourse exemplified in this small project will be needed to achieve the goals that you suggest and the Department of HEW is in a position to encourage, at appropriate times and places throughout this country, such conferences.

PROBLEM ORIENTED RESEARCH - Problem oriented research to the goals of the Department of HEW and our society are certainly valid. The questions to be answered must be carefully formulated lest the answers not be adequate or relevant, which leads to what I believe is one of the most important issues--CREDIBILITY. The data produced by research projects must be creditable in method and conclusion, especially those that are used as a basis of policy and regulation formation. Therefore, this is most acute in areas of research related to the responsibilities of the Department of HEW and public policy. Until recently I was a practicing physician, and let me detail to you again how difficult it is to separate, for patients, the periodic nonsense that comes as the basis of policy decisions of the Department from valid research which should, in fact, change the citizens' health care practices. One is in the position of having to negate part or some of the activity because it is clearly invalid, and to convince people that from the same source other information is valid.

I do not need to recall to you the history of the Department over the past decade and the numerous instances in which major policy decisions

affecting large numbers of our citizens (creating tremendous amounts of anxiety) within short times proved to be useless, based on faulty information from experimental models which would not stand the very basic tests of a sophomore science student. This must be one of the priorities in the development of a long-term policy for research and the utilization and intergration of that research activity.

In my opinion, we are fast drawing to a time that the faith that the public will have in science and especially science and government will have reached such a low level that even valuable data produced will fail to change the practice and life styles.

We look forward to the opportunity of participating in the National Conference on Health Research principles and stand ready to assist in any possible way the task that you have undertaken in developing a health research strategy.

Sincerely yours,

J. Jerry Rodos, D.O. Associate Executive Director American Osteopathic Association

JJR : mt

cc: Dr. Donald S. Fredrickson, Director, National Institute of Health
Donald Siehl, D.O., President, American Osteopathic Association
Dale Dodson, D.O., President-elect, American Osteopathic Association
Edward P. Crowell, D.O., Executive Director, American Osteopathic Association
A. Hollis Wolfe, D.O., Chairman, AOA Bureau of Research

AMERICAN PHARM'ACILLASSOCIATION

. As National Professional Society of Phermacists

WILLIAM S APPLE, Ph.D. Executive Director

August 7, 1978

Mr. Joseph A. Califano, Jr.
The Secretary of Health, Education
 and Welfare
Washington, D.C. 20201

Dear Secretary Califano:

This is to respond to your July 19, 1978 memorandum to professional societies and health organizations requesting their views and suggestions on an HEW multi-year strategy for support of health research.

These comments are submitted on behalf of the American Pharmaceutical Association (APhA) which is the National Professional Society of Pharmacists in the United States. Our membership consists of individual pharmacists practicing their profession as practitioners in community and institutional pharmacies, in pharmaceutical manufacturing, in pharmaceutical research, and in pharmaceutical education, as well as pharmacy students.

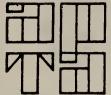
APhA has had a deep and long-standing interest in health research, and we strongly support the current effort to develop a clear Federal government policy in this area, as well as a long range strategy for implementing it. As recently as 1975, the American Pharmaceutical Association, at the request of the President's Biomedical Research Panel, examined this issue in depth. With the advice and consultation of our Academy of Pharmaceutical Sciences and Academy of Pharmacy Practice, APhA in October of that year prepared and submitted comprehensive comments on the subject of biomedical and behavioral research. Appended to this letter is a copy of those comments, as well as an editorial on the subject, both of which were published in the November 1975 issue of APhA's Journal of Pharmaceutical Sciences.

These comments of the Association, although nearly three years old, still accurately reflect APhA's suggestions and concerns as they relate to the formation and implementation of a national health research policy and they are, therefore, extremely relevant to the Department's current effort. We urge that they be given serious consideration in preparing the Department's proposed principles for the October 3-4 National Conference, and we would appreciate receiving a copy of those proposed principles in advance of the Conference.

Thank you for the opportunity to submit our views on this important HEW effort.

> Sincerely, Dilliam S. Apple

WSA:rs Enclosures



american physical therapy association

1156 15th STREET, N.W., WASHINGTON, D.C. 20005 • (202) 466-2070

August 31, 1978

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Director

National Institutes of Health Department of Health, Education

and Welfare

Bethesda MD 20014

Dear Dr. Fredickson:

The American Physical Therapy Association wishes to take this opportunity to thank Secretary Califano for circulating his health research principles and allowing us time to consider his proposal and provide comments. The APTA is committed to the encouragement and development of basic research, clinical research, education research, and administrative research in order to advance the body of knowledge in physical therapy.

The federal government is a major factor in the support of health research. A multi-year strategy for basic health research requires long-term dollars. In order to obtain that approval, guidelines should be developed for basic health research relative to the needs of society.

The application of basic research to health care delivery is an important transistion. A higher priority should be placed on the allocation of resources to applied or clinical research. In accordance with the guidelines for basic research, the application of that research to the delivery of health care can best be developed in a clinical setting. A multi-disciplinary health facility can be a very important center of research.

Health professionals interact in this setting by mutually developing and demonstrating new techniques as the result of basic research. A clinic is more adaptable in the multi-disciplinary approach to research than the 'great research universities'. Universities tend to fragment their departments and faculty according to profession and academic status. This atmosphere is not conducive to coordinated research efforts.



Donald S. Fredickson, M.D. Page 2 August 31, 1978

Clinics also serve as working practicums for students in the health profession. These students would have the opportunity to learn of new research and development, and would be more inclined to enter the scientific field.

The Departments of Labor, and Health, Education and Welfare appropriations bill (HR 12929) allocates approximately \$5.2 billion dollars to the Public Health Service. Approximately \$4 billion dollars has been authorized for the Center for Disease Control, National Institutes of Health, and the Alcehol, Drug Abuse and Mental Health Administration.

After Congress passes these appropriations, the Department of HEW establishes funding priorities and publishes the accompanying regulations in the Federal Register.

Eighty percent of the budget is directed toward health research. In studying the five principles, this money is primarily focused on the first three principles: fundamental research in biology and behavior, assurance of opportunities for investigators, and interdisciplinary applications.

We would urge the D-HEW to allocate a higher percentage of the available resources to applied research in the clinics. This increased emphasis would be consistent with the societal direction outlined in the fourth and fifth principles.

Improving the quality and effectiveness of health services can be more effectively implemented in practice. This direction will enable both practitioners and consumers to gain a greater knowledge of the availability and necessity of health care.

Thank you for allowing the health professions to comment on your health research plan. If I can be of further assistance please contact me.

Sincerely,

James R. Clinkingbeard, Director Department of Educational Affairs

JRC/abj



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American Psychiatric Association

1700 Eighteenth Street, N. W. Weshington, D.C. 20009 • Telephone: (202) 797-4900

August 4, 1978

Joseph A. Califano, Jr.
The Secretary of Health, Education, and Welfare
Washington, D.C. 20201

Dear Mr. Califano:

The American Psychiatric Association is most pleased with the stand that you have taken concerning research in general and basic research in particular. Our Council on Research and Development has been very concerned with the lack of research in our field, as well as basic research in medicine. Attached is a copy of a response to the report of the Task Panel on Research from the recent President's Commission on Mental Health. It expresses some of our concerns as well as our needs.

The American Psychiatric Association would be most pleased to participate in the conference which you are planning here on October 3-4, 1978. We do wish that you would send us the proposed principles and we will appoint a delegate to attend this extremely important meeting.

Once more, thank you for tackling these problems and may we assure you of our interest and our willingness to cooperate.

Sincerely,

Henry H. Work, M.D. Deputy Medical Director,

Professional Affairs

HHW/sf

cc: Dr. Melvin Sabshin, Medical Director Members, Council on Research and Development Julius Richmond, M.D. Response to the report of the Task Panel on Research of the President's Commission on Mental Health from the APA Council 21 Research and Development

We would endorse the very thorough and insightful report of the Research Task Panel of the President's Commission on Mental Health. Even though funds for general medical research have increased by one billion dollars in the last eight years, the Task Panel Report documents that mental health related research has stagnated and indeed the actual buying power for mental health research has decreased by 20% since 1969 (note that the research budget of NIMH has dropped by 35%). Currently only 20% of ADAMHA's budget goes to research (down from 50%, ten to fifteen years ago). In 1969 NIMH was unable to fund 15% of approved meritorious grants; in 1975 it could not fund 45% of these very necessary grants. The consequences are clear. Fewer people are doing research and those that are, are doing so with outmoded equipment and insufficient funds. The cost to the nation from mental illness, drug abuse, and alcoholism is staggering. There is a great need for research to find better prevention and treatment. The national research effort is grinding to a halt due to an eight year period of budget cuts. We are particularly concerned by the lack of funds to train research psychiatrists and would reinforce the concern of the Task Panel with funding of research training. The Task Panel of the President's Commission recommends an increase in the research budget for NIMH of 30 million, for NIDA of nine million, and for Alcohol Abuse and Alcoholism of nine million.

To get better mental health care, the Task Panel recommends, and we would endorse this, that at least this degree of increased research funding is needed. The Task Panel finds that research funding has lagged far far behind that of general medicine in the last eight years. We would endorse the finding of the Task Panel to the President's Commission and urgently recommend that the call for increased funding for psychiatric research be implemented.

AMERICAN PSYCHOLOGICAL ASSOCIATION 1200 SEVENTEENTH STREET, N.W. WASHINGTON, D.C. 20036

Telephone: (Area Code 202) 833-7600

August 7, 1978

The Honorable Joseph A. Califano, Secretary Department of Health, Education, and Welfare Room 615 F, Hubert H. Humphrey Building 200 Independence Avenue S.W. Washington, D.C. 20201

Dear Secretary Califano:

At the American Psychological Association, we read your May 15th speech announcing the development of health research planning principles for the DHEW with a great deal of interest. We look forward to participating actively in this essential step toward a viable five-year health research plan.

The five principles which you suggested in your speech are all laudable, although, as you indicated, your fifth principle may be difficult to implement. Certainly we would all agree with you that the first basic principle should be to maintain at a high level and to enhance support for fundamental research into biology and behavior. Dr. Frederickson, however, in his first draft of suggested NIH principles, took a narrower and predominantly biomedical approach. Further, your July 19th memorandum, to which we are now replying, spoke of the importance of research generally, but specified only biomedical research. By omitting reference to behavioral research, which is an essential component of health research and which is, in fact, supported throughout DHEW, your memorandum created the impression that behavioral research is perceived as less important than biomedical research, or that it is only included as an afterthought.

We feel that the first and most important health research principle must be, as you noted in your speech, the promotion of both biomedical and behavioral research of top quality. It is critical that behavioral research be noted as essential in health research on a fundamental level. Special care will need to be taken to specify behavioral as well as biomedical research in the development of all principles and in all discussions of them, not because behavioral research is more important, but because it is equally important and has been under-recognized by DHEW in previous years. The problems of health and well-being, which are more than the absence of illness, involve many scientific disciplines - physical, behavioral and social. Solutions to these problems therefore require research and collaboration in many fields.

Other areas of concern which we feel should be addressed in the development of health research principles include the needs to: (1) support the best research and training in all areas of basic behavioral and biomedical science; (2) support investigators just entering the field; and (3) focus on the biomedical and behavioral aspects of prevention, as an alternative preferable to "cure."

We would appreciate receiving copies of proposed principles as they are developed within

The Honorable Joseph A. Califano August 7, 1978 Page Two

the Department. We also look forward to the opportunity of submitting further principles for your consideration prior to the October Conference.

Sincerely yours,

Charles A. Kiesler, Ph.D.

Executive Director

CAK: sac

THE AMERICAN SOCIETY FOR THE ADVANCEMENT OF ANESTHESIA IN DENTISTRY

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Executive Secretary, A. REYRS-GUERRA, 475 White Plains Road, Eastchester. N.Y. 10707 (914) 961-8136

September 8, 1978

Joseph A. Califano, Jr. Secretary
Department of Health,
Education and Welfare
Washington, D.C. 20201

Dear Mr. Secretary:

Due to previously made commitments it will be impossible for me as Executive Secretary of the American Society For The Advancement of Anesthesia In Dentistry to be present at the Conference On Health Research Principles to be held in Rathesda, Maryland this coming October 3rd.

I would like to take this opportunity to express the thoughts of our Society, so I am taking the liberty of enclosing for your perusal me of the concepts that we feel are extremely important.

Sincerely yours,

Dr. Antonio Reyes-Guerra Executive Secretary

ARG: vr encl.

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THE AMERICAN SOCIETY FOR THE ADVANCEMENT OF ANESTHESIA IN DENTISTRY

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Executive Secretary, A. REYES-GUERRA, 475 White Plains Road, Eastchester. N.Y. 10707 (914) 961-8136

Suggestions For The Awarding of Research Grants
In The Field of Dentistry

In the past, almost all Federal Grants for research have been awarded to teaching institutions or groups affiliated with a teaching institution. We have no record in the field of dentistry of any grants being awarded to individuals, or to small dental societies. This has, in our opinion, limited the development of private investigation and research, and made it difficult to present findings in a truly objective manner. In Dentistry we must consider that our private patients are influenced by some factors which are not involved when they are treated in educational institutions. These could be summarized as follows:

Economic Consideration: Patients that present themselves at dental schools and clinics are well aware that due to the very nature of these institutions they are subject to the dispositions and concepts of the dentists extending the care. While they do have the option to refuse treatment entirely, they rarely do. It could be stated that they are mentally and psychologically attuned to accepting the treatment they receive. This submission to the dictates of the professional rendering the care is of course common whether the patient is in a private office or an institution. However, in a private office there is considerable room for discussion and choice of alternate methods. One of the major factors in a private office is economic. The cost to the patient. This may often be the determining factor.

Fear and Apprehension: It would seem that fear and apprehension may play a much greater role in determining the extent of clinical care than the economic factor. Surveys of the acceptance of dental care by servicemen where economic factors do not enter into the picture seem to indicate that by far the greatest deterent to dental care is fear of pain. Dentists will readily agree that this is true, however, very few (relatively) take the necessary steps to assuage this condition. The constant improvement in dental technology and materials pushes this aspect aside and neglects to give it the importance it deserves. After all, no matter how perfect our technique or the materials we use, they are of little use if the services cannot be delivered.

President
Julian Bemko, Union, N.J.

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THE AMERICAN SOCIETY FOR THE ADVANCEMENT OF ANESTHESIA IN DENTISTRY

Formerly A.S.A.G.A.D.

Founded 1929 - M. HILLEL FELDMAN, D.D.S.

Executive Secretary, A. REYES-GUERRA, 475 White Plains Road, Eastchester. N.Y. 10707 (914) 961-8136

Personal Rapport: Missing in most institutions is the most essential link between the public and the dental profession, the personal bond. In so many of our institutions the patient often does not know the name of his doctor, and on one day it will be Dr. "Jones" and the next time it might be Dr. "Smith". This lack of continuity requires that each succeeding doctor face a patient who needs to be convinced once again of the doctors good intentions and skill. Confidence has to be re-established and this may take several visits. This lack of personal bond between the doctor and his patient may have the advantage of objectivity, but does it not change in subtle ways the relationship of patient to doctor? We think it does. So much so that studies of patient behavior and reactions made at large institutions, which undoubtedly of scientific value are not as useful as we might think. Certainly they form a base, but we also need observations and research done in the office of the private practitioner. The control of pain should be studied at grass roots level and every effort made to encourage the emergence of lively painless dentistry.

Choice of Treatment: The old adage "the right way is the only way" does not apply in every instance, particularly when we are dealing with human beings. The reactions of the patient as well as his economics will often have a significant bearing on the type of treatment required. We all should try for excellence, but for the private practitioner he often must tailor his delivery to the patient's needs and desires. This is not only necessary but, if it does not violate ethics and result in lowering of standards, is good dentistry. Clinics have budgetary problems which limit the type of care extended, so although their economic factor is not on an individual basis, it still affects the delivery of health care to the individual. The obvious difference being that in the private office the patient has a voice in the decision, whide in a public institution the patient has none or little choice.

It is the contention of our Society, therefore, that the government should assist a recognized Society such as ours, which incidentally is the oldest organized continuing dental society on anesthesia in the country, in basic research in individual offices for the average dental patients in order to assess the reactions and use of the many pain control

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Executive Secretary, A. REYES-GUERRA, 475 White Plains Road, Eastchester. N.Y. 10707 (914) 961-8136

(anesthesia) techniques that are presently available. There will be no experimentation on the patients which might add to the risk of the procedure. However, tried and safe drugs will be utilized a great deal more freely in order to evaluate and gage the patient's reactions and response in the environment of a private dental office to the new techniques utilized in modern pain control.

It is our contention that grants extended for this very purpose will benefit the delivery of dental care to a vast majority of the population of this country.

As far as we know at present, the Federal Government and the State Government have no provisions for research grants to private individual dental practitioners under the auspices of a Society such as ours. We would like to see this remedied.

Thank you for the courtesy of extending us an invitation to participate, and we trust that we will be in further communication with you regarding our position.

Dr. Antonio Reyes-Guerra
Executive Secretary
American Society For The Advancement of
Anesthesia In Dentistry



2.400 East Devon Atende a Suite 248 a Des Plainet Illinot (4018 u.) 4,7,207 - 4.

August 4, 1978

Secretary Joseph A. Califano, Jr.
Department of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

The following remarks are precipitated by your July 19, 1978 memorandum to professional societies and health organizations.

Please accept this as our request for a copy of the proposed principles to be developed by the National Conference to be held October 3-4, 1978 at the National Institutes of Health.

We address ourselves to the use of hypnosis in research, especially research in the behavioral sciences, which are so far in arrears of our scientific knowledge.

To be able to predict those individuals at risk for any given disease or condition, would be to elevate preventive medicine to the number one slot, by recognizing human behavior as an equal of scientific medicine. After all, the human being is a psycho organic unity, with each portion of equal importance. However, to date, our knowledge of human behavior is too sparce to accurately predict an individual's response to a given situation.

It is well established that hypnosis is a normal part of science. Therefore, as a research tool, it can aid the study of the behavioral sciences, since it has the capacity to modify and/or control all aspects of the human body. Consequently, whether the research is directed to the human behavior or an organ, or to biochemical; bioelectrical; neurohumoral; biomagnetic; autonomic or somatic nervous systems; structural parts; adaptive processes; sleep mechanisms; or to any psychological process such as emotions; stress states; motivation or pain, hypnosis can make its contribution within the framework of the scientific project.

A specific contribution is a control group to the usual control group of any study, for the hypnotic control group represents performance up to 100% of the individual's capacity, while the performance of the usual control group varies with the individual's mood and motivation of the moment. In other words, hypnosis provides a means for controlling variables.

Since hypnotic states are neurophysiological models, hypnosis has the capacity to set up a "pure state" of any condition - psychological or physical. Here, then, is a valuable tool in which any neurophysiological model could be studied in its "pure state" without interference.



Page 2 August 4, 1978

Secretary Joseph A. Califano, Jr.

As the behavioral sciences gradually moved to an equal place with scientific knowledge, so would hypnosis move from its present place primarily as a therapeutic tool, into more of its multifaceted usefulness in research of the behavioral sciences.

In conclusion of the above - hypnosis, because of its discriminative ability, affords an experimental tool for penetrating the bewildering maze of human behavior and makes valuable contributions in revealing hidden factors in this complex area.

Medical doctors are traditionally conservative, therefore those who are the least knowledgeable about hypnosis will be the most skeptical of the above thesis. However, doctors who have learned and use hypnosis clinically, will immediately recognize its value as a research tool. (Which the A.M.A. recognized as a scientific therapeutic tool in 1958.)

Changes in research priorities occur so rapidly that only some broad examples of uses of hypnosis in research will be offered here. Thus studies:

- 1. of emotional and physical control (examples: smoking; overweight; alcohol; drug abuse; homograft retention; renal dialysis; cardiac arrhythmias.)
- 2. in social psychology
- 3. in learning and memory
- 4. in pain control of chronic and acute pain including terminal cancer, and mechanisms of
- 5. in sleep patterns
- 6. predicting personalities at risk for various diseases and conditions.

Suggestions for long range strategies for support for Health Research: (I agree with the five principles outlined in Secretary Califano's address to the American Federation for Clinical Research in San Francisco, April 29, 1978.)

 The life sciences should join forces with behavioral sciences in order to inch preventive medicine toward the same quality as that of curative scientific medicine.

Here, the contribution of hypnosis would be in the reduction of illness, thus mortality and cost. Also of importance would be the reduction of time in gathering information. Hypnosis is a tremendous time saver.



Page 3 August 4, 1978

Secretary Joseph A. Califano, Jr.

In making grants for research in any area where hypnosis could make a contribution, HEW could suggest its incorporation into the project.

- Funds for an expanded education program to teach hypnosis to more individuals.
 - a. Doctors of medicine, dentistry and psychology are taught the optimal clinical applications of hypnosis by qualified teachers of hypnosis, in their respective fields.
 - b. Health personnel (paraprofessionals) are taught symantics, such as "The Principles and Clinical Application of Language as a Healing Art."

It is important to increase the numbers in both groups, but as of now there are few valid courses for paraprofessionals. In consequence, lay hypnotists, who of course are not trained in medicine and psychology, are filling the void to the detriment of quality, if not of safety.

Sincerely,

Esther E. Bartlett, M.D.

President

EEB/mmw

American Society of Hematology

1978

Pineidant

DR RALPH O WALLERSTEIN 3838 California Street San Francisco, California 94118 (415) 668 0160

President Elect

DR ERNEST BEUTLER

City of Hope Medical Center
1500 E Ouarta Road

Ouarte California 91010

Vice President

DR ALVIN M MAUER

SI Jude Children's Research Hisspital
332 N Leuderdale
Meniphis Tennessee 38101

Secretery

DR. THOMAS B. BRADLEY Veterans Administration Hospital (151 A) 4150 Clement Streat San Frencisco, California 94121 (415) 221 5450

Treesurer

DR EUGENE P. FRENKEL University of Texas Southwestern Medicel School 5323 Harry Hinas Blvd Oellas, Texas 75235

Historien

DR. THOMAS HALE HAM Oartmouth School of Medicina Hanover, New Hempshira 03755

Councillors

DR. MICHAEL C. BRAIN McMaster University Medical Center Hemilton, Onterio, Canada L8S4J9

DR. PAUL A CHERVENICK University of Pittaburgh School of Madicine Pittsburgh, Pennsylvania 15281

DR. DONALD R HARKNESS University of Miami Miami, Florida 33137

DR. HARRY S. JACOB University of Minnesote Medicel School Minnesote 56456

Ohio State University Columbus, Ohio 43220

DR. RALPH L NACHMAN
Cornell University Medical College
New York New York 10021

DR DAVID G NATHAN
Children's Hospital Medical Center
Boston, Massachusetts 02115

DR. IRWIN M. WEINSTEIN 465 N. Roxbury Oriva Beverly Hills. California 90210 August' 44, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education & Welfare Washington, D.C. 20201

Dear Secretary Califano:

Our Society is grateful for the opportunity to participate in the discussion about the proposed multi-year plan for health research. We are in full accord with the principles that you outlined in your address to the American Federation for Clinical Research in May 1978. Implementation of these principles will require continuing imaginative leadership and the marshalling of views from all segments of society that are concerned with biomedical research and health care. We offer for your consideration our views in the following areas:

- l. We endorse your desire to provide ample opportunities for young investigators. We believe that a major defect in present training programs is a lack of support for many promising young investigators to bridge the gap between the completion of formal training and the development of true independence. We believe that programs to correct this deficiency would attract more serious young men and women into training programs and would do much to reverse the present devastating truncation of academic careers.
- 2. In keeping with your desire to promote interdisciplinary cooperation in biomedical research we suggest that techniques be developed to encourage some trainees in the basic sciences to enter clinically relevant fields of inquiry early in their training programs. Potential benefits of such a system include: a) The range of opportunities for basic scientists would be expanded and, for many, careers might provide greater personal satisfaction;

- b) The clinical sciences would profit from the infusion of tough-minded scientific disciplines with a consequent enhancement of the quality of research.
- 3. As a subspecialty society we offer a strong endorsement of your desire to move away from the "disease-of-the-month" concept in the allocation of the limited resources for the support of research. Quota systems are often arbitrary and may bear little relation to the needs of the nation or to the state of the art. Fashions in biomedical research should be determined more by what is possible (the state of the art) than by what is desired. We believe that investigatorinitiated research with peer review keyed to scientific merit rather than quotas offers the best assurance that the research dollar will be spent most wisely and productively. A second, yet substantial benefit would be the encouragement of the subspecialties to abandon their current "special interest" stance and join forces to strengthen the biomedical research establishment.

We have taken your request for our opinion most seriously and have solicited the view of all members of our executive councils. Owing to vacation schedules and the conflict of an international congress in hematology we have not yet heard from many of these esteemed advisors. We would like to have the option of submitting supplemental material that might be considered at the forthcoming National Conference in October.

Sincerely,

Ralph O. Wallerstein, M.D.

President

ROW:ps

The American Society of



Plant Physiologists

9650 Rockville Pike,

Bethesda, Maryland 20014

U.S.A.

Tel. 301-530-9474

August 21, 1978

Dr. Donald S. Fredrickson, Director National Institutes of Health Department of Health, Education, and Welfare Bethesda, Maryland 20014

Dear Dr. Fredrickson:

In response to your request for outside input on your National Conference on Health Research Principles I submit the enclosed comments. My remarks deal with the need for long-term support of investigators in the biomedical fields as well as pointing out a specific research area where plant scientists should be involved.

If my remarks are not appropriate for the Conference please return them.

Sincerely yours,

G. R. Noggle, Ph.D.

Business Executive

GRN: jb

enc.

Fundamental Research

The Department of Health, Education, and Welfare through the National Institutes of Health has not been a major supporter of plant physiological research. The usual response to plant scientists submitting grant requests to NIH is that there are more appropriate agencies (USDA, EPA, DOE) in the business of supporting basic plant science research. There are, however, some exceptions and NIH has provided long-term research support to a number of plant physiologists. A major feature of this support has been the commitment of funds for a number of years rather than in yearly increments. The long-term support provides continuity to the research effort and allows for the best use of personnel and facilities. This feature of research support should be expanded in future NIH research grants.

Recently a new problem of biomedical concern has developed because of the widespread use of potentially harmful chemicals in industry and agriculture. It is the agricultural problem that I wish to expand on since it illustrates the need for a long-term cooperative research effort between plant physiologists and biomedical scientists. The relationship of this problem to human health has been documented but no major research effort has been initiated.

Many different kinds of chemicals are applied to plants to control insects, fungi, bacteria, nematodes, and weeds; to alter plant form or growth habit; to modify metabolic pathways; or to change their chemical composition. As modern agriculture responds to the need for increasing production of food, fiber, and fuel, the use of chemicals will increase. For some purposes it is sufficient that the chemical be applied to the outer surface of the plant to protect against insects, fungi and bacteria. In other instances the applied chemical must be absorbed through leaf or root surfaces and then transported within the plant before biological activity is achieved.

The relation between chemicals used on plants and animal or human health has not gone on unnoticed. Many fungicides, bacteriocides, and insecticides are known to have harmful effects on man or other organisms and their uses have been restricted or prohibited. These chemicals usually are applied to external plant surfaces and their effects are expressed at the plant surface. The deleterious effects of such chemicals on man can be minimized by appropriate application techniques and pre- or post-harvest treatments. The possible human health hazards of such chemicals remains a concern of the manufacturers, the Environmental Protection Agency, and to a lesser degree, the US Department of Agriculture.

Chemicals applied to plants for weed control, for the alteration of metabolic pathways, or the modification of form or growth habit must enter the plant before an effect is expressed. The chemical is absorbed through root or leaf surfaces and then is transported within the plant to a sensitive target site where some biochemical event is triggered. The chemical at the target site generally is not the same chemical applied to the plant. During absorption and translocation the chemical is in contact with biochemically active cells which alter its structure and biological activity. For example a synthetic auxin such as 2,4-dichlorophenoxyacetic acid (2,4-D) a widely used weed killer, may form conjugates with free amino acids or sugars, may form esters with plant alcohols, may be decarboxylated, hydroxylated, dehydrogenated, or other changes. Studies where isotopically labeled auxins have been applied to plants have shown the plants to contain 20 to 40 different labeled compounds after relatively brief periods of time. In experiments where the same labeled compounds were feed to laboratory animals similar arrays of labeled compounds were found in animal tissues and body fluids.

When it is recognized that dozens of chemicals are routinely applied to plants (not simultaneously) the numbers and kinds of compounds which may be present in plants assumes some significance. In most instances the effects of these compounds on humans, livestock, birds, fish, etc. are not known. It might be mentioned that the biological action of most chemicals applied to plants is poorly understood. Following application a plant may die, may become chlorotic (lose chlorophyll), may grow abnormally, may shed certain organs (leaves, flowers), or undergo some other change in growth pattern. It is not known, however, whether the observed effects are due to the compound originally introduced in the plant or to some metabolite developed within the plant. The active molecule may not be directly related to this introduced chemical but may be a molecule formed by some metabolic pathway activated or repressed by the introduced chemical.

Whatever may be the fate of the applied chemical within the plant, the possibility exists that the altered metabolism, or some specific metabolite, will have an influence on human health. It only is recently that techniques have become available for studying this problem. The techniques of chromatography, spectrophotometry, mass spectrometry, NMR spectrometry, and so forth now enable one to isolate and identify biologically active molecules. Once active molecules have been identified they can be synthesized and tested for biological activity in a number of test organisms.

It is likely that the fate of a particular chemical in a plant such as wheat may be different from that in spinach. In wheat it is the grain that is harvested and used for food while in spinach the leaves are used. Also the conditions under which plants are grown will influence plant metabolism. Thus moisture stress, mineral nutrition, temperature and intensity of radiant energy all influence plant growth and development.

From what has been said it is clear that this is a complex problem; one that needs a continuity of research effort over a period of years. A short "crash" program will not be productive. The problem is typical of many biological and biomedical research problems that require research over a period of years before significant results can be obtained. Agencies responsible for funding research must be aware of the long-term nature of a great deal of modern biological research and be prepared to commit adequate funds over a number of years. Also the plant chemical problem illustrates another aspect of modern biological research — the need for expensive and sophisticated equipment. Most university laboratories have not been able to keep up with inflation and the increased costs of maintaining equipment now on hand. The purchase of new equipment is extremely difficult. Here again agencies funding research must be aware of the increased cost of carrying out reserach and support the investigation adequately.

G. R. Noggle, Ph.D.American Society of Plant Physiologists9650 Rockville PikeBethesda, Maryland 20014

AMERICAN SOCIETY FOR MICHOBIOLOGY

ROBERT F. ACKER, Executive Director 1913 I STREET, N.W. WASHINGTON, D.C. 20006 (202) 833-9680

7 August 1978

The Honorable Joseph A. Califano Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

We appreciate the invitation and welcome the opportunity to respond to your letter of 19 July. The statements which follow have been developed by Dr. C. D. Cox, Chairman of the Public Affairs Committee of the American Society for Microbiology (ASM) and have been approved by Dr. Edwin H. Lennette, President, Dr. Willis A. Wood, President-Elect, and Dr. Harlyn O. Halvorson, a Past President, of the ASM.

Problems of expanding health needs and costs coupled with limited resources confront all of us, and the American Society for Microbiology has been deeply concerned about such matters. We applaud your intention to develop a multi-year strategy for a solution to these problems, and we are sincere in our desire to contribute in every possible way to the evolution of a plan more effective than past "five-year plans" and "forward plans."

Your remarks before the American Federation for Clinical Research meet with our general concurrence, and we wish to respond with the short lead time available with points relating to your five principles. As you might anticipate, we fully endorse the first three principles. We also concur with the last two principles, provided that they are properly implemented.

Basic research provides the foundation for a brighter future, but the fruits of basic research are not predictable, and the research itself must proceed with a high degree of uncertainty. Basic research is by nature an investment in the future, but one which has historically paid off handsomely for the public good. You mention the development of the Salk and Sabin polio vaccines as examples of the fruits of NIH-supported research. These are excellent examples of medical research benefiting mankind, but vital to the success of such efforts were the earlier results of basic research which indicated that there were only three antigenically different polio viruses and that all could be grown to high yields in tissue culture. Without such knowledge, the Salk and Sabin vaccines could not have been developed. Since basic research results cannot be predicted, nor potential significance of such results appreciated or foreseen, basic research must not be fettered by unreasonable constraints. Creative research must not be made subject to the usual rules of scientific program management. Unfettered research in the basic sciences is crucial to the generation of new ideas for the public good. Promising basic research results can later be tested through targeted and applied research. Basic research can only be encouraged through investigator-initiated research grants. Interdisciplinary

research should be supported, but not at the expense of disciplinary project research; for the former is only as sound as the latter is strong. In the health field, some means must be found to insulate basic research from the title funding flux associated with societal needs. One mechanism is to relegate a prescribed fraction of the total health budget to basic research. Another is to adjust the allocation for basic health research annually, with ample consideration for inflation, etc. Whatever procedure is ultimately followed, basic research in the health sciences must be nurtured and stabilized, and we would welcome the opportunity to participate in deliberations toward such goals.

Research on the application of fundamental knowledge to the solution of health problems, i.e., applied or developmental research, is also important, because without it the fruits of basic research would never reach the public. In contrast to basic research, developmental research supported by public funds may be expected to be influenced by the pressure of societal needs. Applied research of this sort is crucial to the transfer of fundamental knowledge arising from basic research to technologies benefiting the public, and its success depends upon scrutiny by the same type of peer review process which has been so effective in identifying innovative basic research in the health sciences.

Improving technology transfer may require even more applied types of technological development or research. The first challenge is to identify target areas where support should be given, but the second and more important problem is how to get the results of federally-funded basic and applied health research into the market and available to the public. In this connection we call to your attention a recent editorial by William D. Carey in the 30 June 1978 issue of Science, which attributes the bottleneck in part to the government's patent policy which stifles market incentive. This matter should be vigorously investigated.

One must keep in mind that different types of professionals from those usually associated with the basic sciences are needed for improving health care delivery, as described in your last two principles. We favor development of such needed disciplines, and we encourage research in these areas, provided it is developed to the same level of scholarliness as in the basic sciences. New research and training programs should be subjected to the same rigorous peer review process which has resulted in the present high competence of our research efforts in the basic health sciences. Indeed we are not per se in opposition to the establishment of a National Institute of Health Care Research, but we are firm in our opposition to having research in the basic sciences dependent in any way upon it.

We support your intention to reexamine the distribution of our research resources among various health components. Our feeling has been that the overlapping jurisdiction between federal agencies has contributed greatly to the ineffectiveness of some programs and to increase in health costs. We would urge the centralization of authority wherever possible, even within agencies. For example, we favor strengthening the authority of the directorship of NIH and cite the division of authority of the National Cancer Institute as an example of unnecessary cost and burden.

The causes of cost increases must be prudently examined, not only in health care delivery, but also in research in the basic sciences. U.S. research equipment is aging, research and training facilities are shrinking and falling apart, and travel support is dwindling. Of particular concern is the crisis generated by soaring indirect costs, or overhead rates. Funds derived from overhead are apparently unavailable for obvious application to the maintenance of experimental animals or the repair and maintenance of equipment. Total dollars for research in the basic sciences may be increasing, but constant dollars available for research at the investigator level are decreasing.

We share your concerns and applaud your goals, and look forward to further dialogue over the next few months. Please call upon us any time as you pursue your important task.

Sincerely,

Robert F. Acker, Ph.D.

Cobert F. Acker

RFA: bmb

Institute for Social Research Center for the Study of Population The Florida State University Taliahassee, Florida 32306



August 3, 1978

Mr. Joseph A. Califano, Jr. The Secretary of Health, Education and Welfare Washington, DC 20201

Dear Mr. Califano:

As Chairman of the Section on Population of the American Sociological Association, I am pleased to respond to your request for views and suggestions on principles that might guide a multi-year strategy for allocating federal health dollars.

Initially, I would like to endorse, in general, the principles which you enunciated before the annual meeting of the American Federation for Clinical Research in San Francisco on April 29. While they were proposed as tentative principles, I think they constitute a reasonable and fundamental set of guidelines which can be elaborated and modified as needed.

Furthermore, I wish to comment particularly on three statements which were included in your remarks. First, you argued for diversity in health research and stressed the need for more emphasis on the population-based life sciences. We in the social and behavioral sciences are especially sensitive to the relative lack of emphasis on these sciences in federal health support and commend you for making this point. Health problems are very much behavioral problems and both material goods and natural science research can only have maximum effect in improved behavioral contexts. Second, priority areas should change as partial solutions are discovered for old problems and new problems become more evident. Your argument for refocusing attention on basic problems is, therefore, well taken. For example, societal changes resulting from population dynamics hearald the need for greater emphasis on health issues concerning the aged and the causes of morbidity and mortality which typically plague them. Third, the requested substantial budget increase for the National Institute of Child Health and Human Development is meritorious. However, that agency continues to limit its population concerns too much to matters of fertility control. Other aspects of demographic change--including morbidity, mortality, migration, and urbanization--have profound health consequences but receive relatively little research support by NICHD.

Mr. Califano Page 2 August 3, 1978

I would be pleased to elaborate on these thoughts at an appropriate time, and would welcome being informed about the set of principles that will be developed.

Many thanks for the opportunity to be heard on these issues.

Sincerely,

Charles B. Nam, Director Center for the Study of

Population

CBN/ub



THE UNIVERSITY OF NORTH CAROLINA AT 'CHAPEL HILL

School of Public Health Department of Biostatistics The University of North Carolina at Chapel Hill Rosenau Hall 201 H Chapel Hill, N.C. 27514

August 7, 1978

Dr. Donald S. Fredrickson Director National Institutes of Health Public Health Service Bethesda, Maryland 20014

Dear Dr. Fredrickson,

I am writing you in response to Secretary Califano's memorandum to professional societies and health organization on the subject of HEW Multi-year strategy for support for health research. This memorandum was referred to me because I am chairman of the Biometrics Section of the American Statistical Association.

The support for research and for training biostatisticians by the National Institutes of Health has been on a noticeable decline in recent years. The support that exists is small and fragemented among the various institutes. The Institute of General Medical Sciences was once the focal point of training and research support for biostatistics. Currently this institute does not support training. Fortunately training grants in biostatistics still continue in other institutes when the grants can be connected with research programs of interest to the supporting institute.

Research support for biostatistics has not been so fortunate. The Institute of General Medical Sciences, which formerly supported research in biostatistics, has been in a budgetary squeeze for several years and now supports very little research in biostatistics. Most institutes do not have study sections that are appropriate for reviewing proposals for research in statistics. My impression is that research support for biostatistics today is an unwelcome appendage to contracts that have a primary goal of service to other substantive areas. Even when a RFP suggests research is appropriate it is when related to the service activity, the funds allocated are small and they diminish as time passes because of competing needs for funds for other activities supported by the contract. While not completely impossible, it is very difficult to get research funds for biostatistics as a substantive area of health science at this time.

Dr. Fredrickson August 7, 1978 The net result of these depravations is that biostatistics has no focal point for training and research as a substantive area of medical science within NIH. The past contributions of biostatistics to health research and the potentialities for future contributions merit a more organized dependable support for good training and research programs. In his address to the American Federation for Clinical Research in San Francisco, April 29, 1978, Secretary Califano, mentions the need for support of diverse disciplines and specifically mentions biostatistics. A recent Milbank Report on training in Public Health also mentions biostatistics as a key discipline. These recommendations have had no discernable effect on training and research support for biostatistics. In my opinion a careful examination of training needs and the potential research results that are applicable to health related sciences would be useful at this time. The development of the new multi-year strategy for support of Health Research could provide the framework for this activity. Thank you for your consideration. Sincerely, James E. Grizzle Professor JEG/nb cc: Dr. Fred Leone



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Sandy R. Iannotta, Executive Director

August 4, 1978

The Honorable Joseph A. Califano, Jr. Secretary of the Department of Health, Education and Welfare 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Mr. Califano,

Thank you for requesting the views of the American Thoracic Society with regard to your proposal for a Multi-Year Strategy for Support for Health Research.

The American Lung Association and its medical section, the American Thoracic Society, have had major interests in the National Institutes of Health. These organizations have given strong support to the formation and development of the Lung Division of NHLBI as well as strong support for several other institutes. Many members of our organizations are actively involved in NIH committees and deeply concerned about the future. Many lives have been saved and health improved through research supported by the NIH and we have strongly supported increased funding for the current programs of NIH.

We are very interested in the proposed principles but an official statement from the ATS would require review by our Executive Committee. We would greatly appreciate receiving the proposed principles in advance of the October meeting so that we can provide official comments.

Because we received your letter of July 19 only a few days before the August 7 deadline, I cannot make official recommendations for the American Thoracic Society. However, it is my judgement that many members of the ATS would be concerned that your suggested principles #4 and #5 may introduce major changes in one of the government's most successful organizations; the NIH. We strongly support these goals but question the use of NIH to obtain them. The ATS has supported increased

Page 2 of 2 August 4, 1978

The Honorable Joseph A. Califano, Jr.

funding for the current goals of the NIH. If additional goals for the NIH are to be added, the funding should be increased proportionately and a separate budget may be necessary to maintain the current outstanding programs of the NIH.

Respectfully yours,

round I Finney

Donald F. Tierney, M.D. President

American Thoracic Society



THE UNIVERSITY OF TEXAS SYSTEM CANCER CENTER

THE ROLL OF THE PARTY OF THE PA

Texas Medical Center Houston, Texas 77025

August 1, 1978

Mr. Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington. D. C. 20201

Dear Mr. Secretary:

I am in receipt of your memorandum of July 19, 1978, "HEW multi-year strategy for support for health research".

In addition to the general strategies which you have listed, I can see one important principle which one must consider if the dilemma you pose - the balance of needs versus means - is not to continue. I would suggest that whenever a firefighting endeavor is propounded as a "crying need" in health research, that first an assessment be made as to whether or not there is a solid base in fundamental knowledge that will permit logical and efficient development to ensue (your scientific consensus). If there is not, then means should not be committed to any further development in that field until such knowledge is available. While this may not seem politic, it is the politics of tabling premature proposals. In defense of it, I would merely cite the difference in progress between the conquest of polio and the crusade against cancer. The former case satisfied the criterion, the latter did not. In essence, this policy would say that national priorities for health research are modulated by the prospects for achievement rather than solely by the establishment of need.

The above are my personal views and do not represent any institutional viewpoints.

Manley Mandel, Ph.D.

rustee, American Type Culture Collection

MM/jf

Annex and Rehabilitation Center



AMERICAN UROLOGICAL ASSOCIATION, INC.

1120 North Charles Street • Bándore, Marward 21201 Phone: 301-727-1196

August 3, 1978

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Executive Secretary Administrative Consultant Mr. Joseph A. Califano, Jr. The Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Califano:

I am replying to your memorandum of July 19, 1978 concerning "HEW Multi-year Strategy for Support for Health Research."

The text of your talk before the annual meeting of the American Federation for Clinical Research is an excellent document. You state quite clearly the need for research in health related fields and present it more successfully and forcefully than many of us who have been testifying before the Appropriation Committees.

My only comment would be to amplify the statements on pages 10 and 11. In the field of Urology there is a real need to bridge the gap between basic research and the diseases our patients have (kidney stones, benign prostatic hypertrophy, cancer, neurogenic bladder, urinary tract obstruction and infections). Urology has had a problem of insufficient numbers of young men trained in the new scientific research techniques, while the basic scientists who know the techniques are not aware of the clinical problems. This gap can be closed only by developing more urologists who are also good scientists and having available funds to allow them to do the necessary research. There is also a need for better communication between the urologists and the basic scientists.

Sincerely yours,

Jay Y. Gillenwater

Chairman, AUA Research Committee Professor and Chairman Urology

Hay y Illemunder MD

University of Virginia

Medical School

JYG/jh

15300 VENTURA BOULEVARD, SUITE 315 . P.O. BOX 5951 . SHERMAN OAKS, CALIFORNIA 91403 . (213) 990-2151

July 31, 1978

Mr. Joseph A. Califano, Jr. The Secretary, Department of Health, Education, and Welfare Washington, D. C. 20201

Re: Your Memorandum July 19, 1978, on HEW Multi-Year Strategy for Support for Health Research

Dear Mr. Califano:

We are happy to respond to your invitation to comment on the above referenced subject. Our comments are attached. They are also in addition to comments made earlier to the seven panels of the NINCDS-NIH and to our Statement submitted at the Public Forum May 11-12 in Chantilly, Virginia.

Thank you for permitting us this opportunity to participate.

Sincerely,

Robert G. Dicus

Chairman, Board of Trustees

RGD/nj

Enclosures: ALSSOA's Comments HEW Multi-Year Strategy for

Support for Health Research.

cc: Dr. Donald Fredrickson, Director, NIH

H. Eames Bishop, President

Dr. Donald Tower, Director, NINCDS

The future of Federal support for health research is a vital area of concern for all of us. From the point-of-view of the Amyotrophic Lateral Sclerosis Society of America (ALSSOA), as we make our recommendations on the principles which shall ultimately determine the future policy, ALSSOA cannot help but be self-serving in some of these recommendations. We make no apology for this. Instead, we point out that ALS is one of the neglected diseases for the last 100 years and is not one of the "diseases of the Month" that the Secretary made reference to in his remarks.

ALSSOA has elected to focus upon the program elements which were suggested by the Secretary in his five principles as the best way to convey our recommendations for these "neglected diseases of 100 years," as well as the broad spectrum of health needs which cry out for solution. One undeniable economic fact that is never mentioned in these programs of cost-effectiveness decision making is the economic benefit to be enjoyed by achieving some real preventions and cures of these health problems that have plagued our society. Think of the money we could save not to forget the relief of human suffering and disease-imposed destructions of the families.

Before addressing these five principles however, ALSSOA wishes to point out the need for true financial reprogramming and budgeting. Wherein, annual appropriations for increased appropriations for health research may be announced as a dollar increase, the reality of inflated dollars results in a net loss and not a net gain of actual dollars for health research funding. There must be some truth applied in the Multi-Year Strategy of real health research funding support if the goal is to be realistic and meaningful.

The Five Basic Principles

1. TO MAINTAIN AT A HIGH LEVEL AND TO ENHANCE OUR SUPPORT FOR FUNDAMENTAL RESEARCH INTO BIOLOGY AND BEHAVIOR.

ALSSOA'S Comment:

There is no known prevention for ALS, and little research money and time devoted to its etiology. Many medical scientists believe that the answer to ALS may well lie within the following categories or methodological innovations:

- -- Normal biology of motor neurons (biochemistry and physiology)
- -- Neuronal degeneration and response to injury
- -- Neurotropic factors, nerve growth factor, neuronal DNA repair and hormonal factors
- -- Motor system transmitters

- -- Axoplasmic flow and receptor activity of motor nerve terminals
- -- Influences of muscle, nerve terminals, sprouting on integrity of neuronal function
- -- Environmental toxins that affect the motor system
- -- Viruses causing chronic neuronal disease
- -- Neuron specific antigens and immune responses to normal surface antigens or altered neuronal membranes
- -- Pharmacology of drugs influencing motor neuron functions and spasticity
- -- Cell culture systems involving neurons and neuron-muscle interactions
- -- Cell separation procedures

"As Chairman of the Scientific Advisory and Scientific Review Committees of ALSSOA, I will present my personal viewpoint to the Board of Trustees. I think it reflects a concensus of the views of the committees on where our research efforts now stand:

Amyotrophic Lateral Sclerosis remains a disease of unknown cause and a disease without an effective therapy. Indeed, we have insufficient clues to focus on a specific area of research and insufficient knowledge to devise rational therapeutic trials. Since there are many directions in which productive research might be done, until the problem is better defined, I think we must maintain a very broad-based and open-minded approach to research on ALS and related disorders. In general, these approaches could be divided into (1) clinical studies, (2) investigations of normal biology of the motor system and its response to injury, and (3) studies of animal models or of human tissue.

1. Clinical studies - Very few clues in the clinical course, laboratory findings or pathological studies of patients with ALS suggest a cause or effective treatment. Both ALSSOA and the Veterans Administration, however, are funding systematic reevaluation of the clinical disease in hopes of detecting such clues. The even epidemiologic distribution of cases throughout the world also provides little insight into causation. Therefore a study of the higher incidences in Guam or the Kii Peninsula of Japan and the studies of familial aggregation of cases may again provide clues for future research. Other areas of higher

- 3 -

or lower incidence or clustering of cases should be carefully looked for, and the immunogenetic studies now being supported by ALSSOA and by NINCDS may help in this regard.

Testing of therapeutic agents is feasible even without know-ledge of etiology. Therefore, we should continue to encourage controlled therapeutic trials of drugs that have some rationale either for the alleviation of symptoms or attenuation of the progression of ALS. In all probability, however, adequate treatment or prevention of ALS will not be feasible until more is known of its pathophysiology or cause.

- 2. Biology of the motor system and its response to injury -To date physiological and biochemical studies in ALS have not been highly revealing. Studies of cortical motor neurons, anterior horn cells, peripheral nerve, neuromuscular junction and muscle might all be considered relevant. However, since the major impact of the disease falls on the anterior horn cells of the spinal cord, studies of the normal physiology and biochemistry of this cell would seem most relevant. The basic questions of what maintains these cells through normal life and why they might selectively die prematurely is completely unanswered. Therefore, studies of nerve growth factorlike substances which might support these cells or the mechanisms of DNA repair within these cells would be highly relevant. On the other hand, there is a vast area of neurobiology, physiology, peripheral nerve function, end-plate physiology and muscle biochemistry and physiology which, although it may prove to be relevant, would not appear to be an area in which ALSSOA should spend its limited funds at this time, unless the investigator shows a very novel approach, employs new methods, or can justify potential relevance to ALS for the studies.
- 3. Animal models and human tissues - Considerable recent progress has been made in this area. The animal models can be divided in those of genetic nature such as the Wobbler Mouse and the Brittany Spaniel, and those where the motor system is affected by external factors such as toxins or viruses. The Wobbler Mouse has been the major animal model studied in the past, but the recent work with the Brittany Spaniel suggests that it is a disease more closely resembling human motor system disease. Further work is also progressing on toxins which produce similar abnormalities of anterior horn cell and with viruses and immune reactions which specifically involve the motor neurons. In each case these animal diseases must be viewed as means of developing new methodology or insights which could then be applied to patients with ALS or human tissue.

In the past the extensive attempts at virus isolation, biochemical studies of tissue, analysis of tissues for toxins or trace metals, and immunological studies of patients have been largely negative. This does not mean, however, that none of these factors are involved, but simply that search for a different factor, application of a new method, or pursuit of new ideas need to be sought and supported."

The above quotation is from Richard T. Johnson, M.D. Eisenhower Professor of Neurology and Professor of Microbiology
The Johns Hopkins University
School of Medicine

If the needs for health research, as summarized in the Secretary's First Principle, include the recommendations above from ALSSOA, and from Richard T. Johnson, M.D., Chairman of ALSSOA's Scientific Advisory and Review Committees, then ALSSOA supports the Secretary's First Principle.

Additionally, ALSSOA supports related research investigations under the general subject of CNS REGENERATION RESEARCH, AS presently structured in NINCDS, and regeneration of entire body parts as reported by several research investigators including Dr. Robert Becker, Chief of Orthopedic Surgery, Veterans Administration Hospital, Syracuse, New York.

AMPLE OPPORTUNITIES FOR YOUNG INVESTIGATORS.

ALSSOA'S Comment:

ALSSOA supports program funding for training and fellowships for dynamic, young researchers in both the basic and applied research areas, especially for ALS. The broad spectrum of research disciplines relating to biology (genetics, immunology, virology, etc.) should all be served.

At least every five years, a forum for bringing these research persons together to exchange the knowledge of their speciality and the explosion of research progress must be provided for. Similarly, there must be a constant application of proven medical research knowledge and medical treatment procedures from one family of disease to another. An example in the case of ALS would be the application or respiratory life-saving and support methodologies learned in the "polio" years to the life threatening respiratory complications of ALS.

3. BASIC RESEARCH HAS TO BE ACCOMPANIED BY VIGOROUS, THOUGHTFUL AND, WHERE APPROPRIATE, INTERDISCIPLINARY APPLICATIONS.

ALSSOA'S Comment:

In terms of ALS, the void between the researchers in the neurosciences and the clinical neurologists who make the "no cause, no cure, no hope diagnosis and prognosis" is very harmful to ALS patients and families. Furthermore, the world of the diagnosing neurologist is taken as "gospel" by the other clinical medicine physicians who would try to serve the needs of the ALS patient; i.e., internal medicine, general practice, family practice, physiatrist, and other rehabilitation personnel. The "diagnosis of hopelessness" permeates the entire fabric of the health delivery system. The net result is that the patients abandon the delivery system to seek their "miracle cures" from whatever resource. Thus, the biostatistics are not correct since they are derived by extrapolation from neuroepidemiological studies. The clinical physicians refuse to accept the ALS patient for surviving, coping, and living methodologies since the physician, per se, cannot "cure" the disease.

ALSSOA is convening a Clinical Advisory Committee (CAC) of renowned physicians and paramedical specialists to address the need in this vital area until the medical research prevention or cure can be found. The agencies of government charged with the health research responsibility should work closely with groups like ALSSOA's CAC and Scientific Advisory Committee (SAC) to bring the best coordination of research dollars with research programs to bear on the subjects.

4. OUR GOVERNMENT-SUPPORTED RESEARCH MUST HAVE A STRONG ORIENTATION TOWARD IMPROVING THE QUALITY OF OUR NATIONS HEALTH AND EFFECTIVENESS OF THIS NATION'S HEALTH SERVICES.

ALSSOA'S Comment:

The health delivery system must be broadened in both the funding support and delivery system alternatives to embrace the needs of catastrophic illness and long-term care. The present "acute care-crisis intervention" model must provide for prevention alternatives and Home Care with Home Health Aides and other cost-saving methodologies. Advanced technology and bio-medical engineering research, basic and applied, must be broadened and coupled with human research to achieve the desired quality of health. Legislative reforms of Social Security, Medicare, Older Americans Act and SSI, must be better defined, coordinated, implemented and

serving of the needs of health.

New strategies utilizing proven aerospace "spin-offs" and environmental control systems must be available through a nation-wide Equipment Acquisition and Delivery System.

Benefit/cost accountability in these programs must become as necessary as the methodology of solving health problems themselves.

5. HEW-SUPPORTIVE RESEARCH MUST BE MORE EFFECTIVELY ORIENTED TO DEVELOP KNOWLEDGE BASES THAT SUPPORT NOT JUST SOME BUT ALL THE HEALTH MISSIONS OF THE DEPARTMENT -- PREVENTION, DELIVERY, REGULATION, STANDARD-SETTING, AND COST CONTROL.

ALSSOA'S Comment:

Not only should the government research dollars be properly distributed among the different health components and institutes of government research agencies, but also those dollars should also be properly allocated to all of the diseases which have been neglected for so long; i.e., diseases like ALS. ALSSOA's President, H. Eames Bishop, in his remarks to the Open Forum in Chantilly, Virginia has eloquently stated the ALS problem. The full text of his remarks are appended to my comments in support of ALSSOA's position on this entire area of discussion and as specifically relates to the Five Principles set forth by the Secretary.

Thank you.

Respectfully Submitted:
Kakut J. Dicus

Robert G. Dicus

Chairman, Board of Trustees

RGD/nj

15300 VENTURA BOULEVARD, SUITE 315 ◆ P.O. BOX 5951 ◆ SHERMAN OAKS, CALIFORNIA 91403 ◆ (213) 990-2151

September 5, 1978

Donald S. Fredrickson, M.D. Director Department of Health, Education & Welfare National Institutes of Health Bethesda, Maryland 20014

Dear Dr. Fredrickson:

Subject: National Conference on Health Research Principles

I am herewith attaching two pre-registration forms, one for H. Eames Bishop, President of ALSSOA, and one for Area Vice President Elmer Cerin, in connection with your conference to be held in Bethesda October 3-4. I am also enclosing a copy of the report which we filed at the time of the NINCDS Conference held in Chantilly, Virginia, May 11-12. This report, in general, covers the concerns of ALSSOA.

There are, however, other concerns that we feel this conference should deal with, as follows:

- 1. Long-term financing of research. It is both costly and impractical for medical research to be funded on an annual basis, and we believe that funding should be requested for the NIH health programs over at least a three-year period of time. This would allow for the proper planning of research, and, we are certain, would allow for a more efficient expenditure of research dollars.
- 2. As a lay person, I, certainly, am not qualified to enter the controversy pertaining to the division of research dollars between basic and applied research. It does, however, occur to me that any basic research that lends a clue as to application should be immediately followed by applied research. It also follows that some theoretical approaches to applied research may be warranted in some instances.
- 3. Research grant overhead. I have been alarmed by the fact that the monies expended by the federal government for health research grants allow for an indirect overhead sometimes in excess of 50% of the total research grant. Obviously, such a high indirect charge is not attributable to basic and correct indirect charges, and a much lower base and limitation should be established. We know of

many institutions that receive from the federal government a 50% indirect charge for research grants, whereas they will negotiate with the ALS Society and other voluntary agencies as low as onethird of that amount.

It occurs to me that this indirect allowance in such an exorbitant amount is probably intended to help finance medical schools and research institutions in general, and we believe that by budgeting specifically for this purpose, a better control can be had and a fairer representation of research dollars set forth.

Scientific training. In the last few years there has been a decreasing emphasis on the training of medical scientists, and this, we believe, is a policy that is nonproductive. There is a shortage of qualified medical scientists now, and we believe that a program of helping support research scientists' training should be reinvigorated and expanded.

I look forward to cooperating and working with you in any way to better the health of this nation.

truly yours,

Eames Bishop

President

HEB/mcg

Enc. - (2) Pre-Registration Forms ALSSOA Statement to Public Forum, Chantilly, Virginia, 5/11-12/78

cc: Elmer Cerin (w/encls.) THE ANDREW W. MELLON FOUNDATION

140 EAST 62 MISHREAT

July 28, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

This is in response to your form letter of July 19, 1978, addressed to "Professional Societies and Health Organizations," concerning "HEW Multi-Year Strategy for Support for Health Research." In that letter you solicit the views of the organizations to which it is addressed on the principles the Department should adopt to guide it in making the choices that are necessary.

Although The Andrew W. Mellon Foundation has no formal policy position on these matters, I believe that certain principles can be derived from the pattern of the Foundation's grant-making during the past several years. That pattern expresses a sense of the importance of basic science, of advanced training, of the provision of research opportunities for young scientists, and of research in reproductive biology.

With the hope that this may be of some help to you, and with best wishes -

Sincerely yours,

g. Kunn Smith Jr.

J. Kellum Smith, Jr. Vice President and Secretary



WASHINGTON OFFICE

August 11, 1978

Hon. Joseph A. Califano, Jr. Secretary Department of Health, Education and Welfare 200 Independence Avenue, S.W. Room 615F Washington, D.C. 20201

Dear Mr. Secretary:

Thank you for your letter of July 19, inviting the Arthritis Foundation to respond initially to the five principles concerning this nation's policy on biomedical and behavioral research which you enunciated at this year's Annual Meeting of the American Federation for Clinical Research.

Mr. Clarke has asked me to send to you the results of an Ad Hoc Committee meeting held in Washington on August 3 at which representatives of the Foundation and its two professional sections reviewed the fireprinciples. Foundation representatives attending the meeting were:

W. W. Satterfield, Chairman of the Board, Arthritis Foundation

Joan Sutton, M.S.N., President-Elect, Allied Health Profession Section of the Arthritis Foundation

Frederic C. McDuffie, M.D., Chairman, AF Research Committee

Robert J. Winchester, M.D., Chairman of Fellowships Subcommittee of AF Research Committee

Colon H. Wilson, M.D., Consulting Medical Director, Arthritis Foundation

Roland W. Moskowitz, M.D., Chairman, AF Government Affairs Committee

Clifford M. Clarke, CAE, President, Arthritis Foundation

David D. Shobe, Vice President for Government Affairs, Arthritis Foundation

Others on the Committee who have also reviewed the summary are:

Alan S. Cohen, M.D., President, American Rheumatism Association Section of the Arthritis Foundation

B-108

Hon. Joseph A. Califano, Jr. August 11, 1978 Page two

- Daniel J. McCarty, M.D., President-Elect, American Rheumatism Association Section of the Arthritis Foundation
- David Wayne Smith, D.Ed. President, Allied Health Professions Section of the Arthritis Foundation
- James R. Klinenberg, M.D., Chairman of the Center Grants Subcommittee of the AF Research Committee
- Joseph N. Masci, Chairman, Planning Committee, Arthritis Foundation
- Charles L. Christian, M.D., Vice Chairman, AF Planning Committee
- H M Poole, Jr., formerly Chairman of the Board, Arthritis Foundation

We appreciate the opportunity to provide you with these views and look forward to the October 3-4 meeting to further discuss the implication which the five principles may have for the future of health research.

Sincerely,

David D. Shobe

Vice President for Government Affairs

DDS/st Enclosure The Foundation heartily supports this principle. We would further urge that the integrity of the original mission of the National Institutes of Health, namely the initiation and funding of basic and clinical research, and the preparation of investigators to enter these respective fields, should be preserved. Extreme care should be taken not to dilute this principal mission by adding on new programs which, while they may complement ongoing NIH activities, tend to seriously erode the financial base upon which research and training depend, as well as to distract the NIH administration from its major concern — the biomedical research community. We would, therefore, counsel the Department not to overload the capacity of NIH by burdening it with the solution of the nation's myriad health problems, but rather to encourage and aid it in concentrating on that which it does the best.

For this reason, the Foundation would question the efficacy of NIH becoming involved in behavioral research beyond that defined within the context of clinical research, biostatistics and epidemiology, all of which we would recommend be enlarged in scope. Additional Study Sections should be appointed to review these proposed endeavors with the same scientific standards with which they review basic research proposals.

If the Department wishes to see behavioral research related to health expanded beyond the scientific disciplines currently described in the NIH mission, for example, psycho-social research, i.e., why people smoke, overeat, etc. and why they do not follow a more healthy regimen, the Department may wish to create an Institute of Behavioral Research, which together with the FDA, ADAMHA, HCFA, and other components of the Public Health Service may be placed under a central administration similar to that of NIH so as to collectively rationalize the activities and findings of these agencies and, therefore, make it more feasible to develop a coherent approach to a national health policy.

We would further hope that some fiscal continuity could be accorded the missions of NIH so that those dependent upon research and training funds might be better able to rely upon them. This would enhance long-range planning which is now a near impossibility. It would provide stability to the work of research teams. It would encourage young investigators to remain in the field. It would encourage prospective investigators to enter biomedical research with some assurance that when they complete their training there will be a position in the research community for them and funds by which to accomplish their research aspirations.

Continuity could be further strengthened by providing more five-year grants which allow for a more coherent and rational renewal process. The basis for approval or denial of a renewal mid-way through a three-year grant is often rather tenuous because of the lack of the accumulation of hard data within the first 18 months of the research.

The goal set this year by the House Appropriations Subcommittee on Labor & HEW to finance competing biomedical research applications at the 2.50 level, or approximately 50 percent of approved applications, seems to us to be worthy of establishing as a norm for the future. Arthritis research funding for the past two years has been at approximately 1.80 or 30 percent of approved applications.

We would also concur in a Departmental effort to renew the physical research plant. It is suggested that attention be given to separate budgeting for replacement equipment so as to guarantee that funds will be used for this purpose. The Department may wish to encourage greater collaboration between the Institutes of NIH and the Division of Research Resources in order to promote a shared knowledge of the equipment needs and responsibility for funding these needs between the Institutes and the Division of Research Resources. Greater articulation is required by researchers of anticipated equipment replacement to provide planned funding of this area.

Should such demonstration programs as centers, initiatives in control and prevention, community projects, outreach, etc. be deemed to be a continuing part of an expanded mandate of NIH, then such programs should be carefully and constantly evaluated in respect to their relative benefits vis-a-vis costs. Also, the interaction of these programs with the original mandate of NIH should be measured to assess effective utilization of scarce resources.

Lastly, to preserve the integrity of the peer review mechanism by which basic and clinical research grants are reviewed, it is the Foundation's opinion that applications for such grants should not be subject to review or control by the Health Systems Agencies, although informational copies of research proposals should be made available to HSA's.

Principle #2: "...we must assure that there are ample opportunities for young investigators."

The Foundation also fully supports this principle. NIH training programs for young investigators should be given the highest priority. To encourage young M.D.'s, in particular, to enter research, the Foundation proposes an increased use of the NIH Research Training Grants program, rather than complete reliance upon the Research Service Awards program.

Although the Training Grants program came under intense fire because it was felt that some institutions were using these funds for other than their intended purpose and that many trainees subsequently chose lucrative private practices rather than research, this was not the case in all programs. When the NIH Training Grants program was in its prime, rheumatology had one of the best retention records of all the programs. Over 70 percent of the trainees remained In academic research and/or teaching. There has to be some gamble taken by the government in these programs if the best minds are to be attracted into research. Fellowships are reasonable for support of Ph.D.'s who have already made up their mind to enter research. They also offer the Fellow more flexibility in choosing a training program, especially if he or she wishes to train at a smaller institution unlikely to be the beneficiary of a training grant. However, they offer no special inducement to the young M.D.'s who may want to tentatively try out the research waters before diving in.

Potential physician-scientists are discouraged from entering today's research training programs because of the lack of a progressive research manpower development program which would take into consideration their lack of prior research experience and their special career planning needs. Also of negative influence is the inability of most training programs to assure the physician/researcher of a position at their institution upon completion of their training. Further discouragement is provided by the instability of research funding which penalizes particularly the investigator without a track record upon which to judge his or her capabilities in competition with the senior investigator. And, finally, the pay-back proviso is certainly a deterrent to one who is not yet sure that research is going to be his or her chosen career.

To maintain a flow of quality Ph.D. and M.D. researchers, the current Fellowship stipend should be adjusted upwards toward the level of that enjoyed by the Clincal Associates in the NIH Intramural Fellowship program. One reason for this adjustment obviously is to provide a reasonable standard of living but also it is needed to obviate the young researcher having to seek "moonlighting" opportunities which tend to dilute his time and energies from his research pursuits. Consideration should be given to providing research-project costs along with the stipend. A longer lead time is needed in the awarding of Fellowships so that both prospective Fellows and host institutions may plan their respective programs more intelligently.

Efforts should be made to seek a balance between Fellowship support and Institutional Training Grant support instead of the current mandatory 3:1 ratio which allows very little institutional support. The Training Grants program should be allowed to stand or fall on its own.

A planned progression of successive support programs is needed to attract and hold the best biomedical investigators. One of these programs is the Research Career Development Award which offers temporary security to the new researcher who is of exceptional caliber. The Foundation would like to see increased emphasis given to this program as well as to the Clinical Investigator program.

A manpower survey should be initiated in the areas of epidemiology, behavioral research, and other health research areas to determine what the training needs are in these areas. Special training programs should then be designed to meet the research manpower needs in these areas. In arthritis, we already know the needs. There are only three epidemiologists working in this field and none being trained. There is no epidemiological research in arthritis being funded by NIH.

Principle #3: "Basic research has to be accompanied by vigorous, thoughtful and, where appropriate, interdisciplinary applications.

Collaborative, interdisciplinary research is of particular interest to the Foundation because arthritis cuts across so many of the Institutes of NIH. Unlike many other diseases, arthritis is not a single phenomenon but is a field of over 100 diseases representing problems of inflammation, bone growth, infection, metabolic disorders, dysfunction of the auto-immune system, genetics, connective tissue disease, transplantation rejection and cellular biology. It, therefore, offers many opportunities for collaborative studies in which a variety of scientific disciplines can be called upon for their respective contribution.

Arthritis is a uniquely human disease which requires extensive clinical research and close collaboration between basic and clinical research which is often embodied in the same individual.

The Foundation supports the principle that research findings in one area can often benefit those of another. Arthritis and cancer research, for example, are inextricably linked in respect to immunological research. In the past 20 years, arthritis research laboratories have defined many of the basic concepts in immunochemistry, immunobiology and immunogenetics, as well as metabolic regulation and the structure of molecules making up the connective tissues. Research groups which were initially devoted to the study of rheumatic diseases have formed the basis for many of the world's foremost laboratories engaged in basic research in cancer, heart disease, gastrointestinal disease and nervous system diseases. Likewise, fundamental investigations in connective tissue have received an important impetus from arthritis research units. These efforts have led to an understanding of the way the body is put together, an understanding of genetic defects, structural molecules, and better information for understanding the structure of blood vessels, bone and other components.

Naturally, arthritis research has also drawn upon the work of Cancer, Allergy, Aging, and other Institutes of NIH wherever such research has been inter-related to basic concepts being explored by arthritis researchers.

Based upon these observations, the question arises as to whether the Institutes of NIH should be reconstituted to reflect the significant advances made in understanding diseases since the Institutes were established. A different set of coordinates may need to be developed upon whose intersections key research initiatives can be properly focused.

In many instances it is not the lack of understanding or interest in how "interconnections" can be made "between basic and applications research" but rather the lack of discretionary funds available to the Director of NIH to promote such studies.

There is, for instance, an excellent example in arthritis of how basic research findings can offer unequaled advantages to applied research. In this case, a transfer of knowledge from genetics to epidemiology. It has recently been established that several major forms of arthritis, including Rheumatoid Arthritis and Ankylosing Spondylitis, are influenced by genetic factors. These findings provide major new opportunities to characterize the role that histocompatibility antigens have in increasing susceptibility to arthritis and also to identify the causative factors.

Once this is known, methods need to be perfected for detecting the genetic marker so that high risk patients can be easily identified. Studies can then be designed to characterize Rheumatoid Arthritis, the most severe form of arthritis, and other inflammatory types of arthritis, with regard to the presence or absence of the marker, the severity of the disease, its progression, etc. These studies will only be of value if they are carried out on a sufficiently large scale to provide significant subgroupings. This means a large number of patients and investigators. These studies could have a major impact on diagnosis and treatment of these diseases. It is premature to predict the effect on prevention.

The course suggested from basic to applied research is in this instance being blocked by insufficient funds. It is the Foundation's estimate that this is the cause of other failures to readily utilize basic research findings, not a lack of interest to do so. If research priority scores were to attain the 2.50 level cited in our response to Principle #1 as a realistic goal, then it is opined that many good applied research projects would automatically be funded.

The Foundation also suggests that there is a need for improved collaboration between Intramural and Extramural Research at NIAMDD and between the Intramural Research programs of all the NIH. There is no reason for these programs to be so separate.

In order to better plan for Inter-Institute studies and other collaborative research ventures, some long-range policy-making body needs to be constituted to review the recommendations arising out of the various Inter-Institute Coordinating Committees. The Foundation believes that one possibility may be an expansion of the role of the NIH Study Sections beyond their review of current research. Their expanded mission would be to provide estimates of where research advances can be most readily achieved by proper investment.

Principle #4: "Our government-supported research must have a strong orientation toward improving the quality of our nation's health and effectiveness of this nation's health services."

The holistic approach to medicine has assumed an increasing interest and importance to the Foundation which has recently established a Patient Services Section. Arthritis patients often have severe emotional problems which are an outgrowth of the progressive, chronic, debilitating nature of the disease with its pain, increasing lack of mobility and possible deformity. The relationship of these problems to the disease is not fully understood and little is being done to investigate them. The failure of health professionals to deal with this aspect of the disease has caused patient clubs to spring up across the country which are designed for patients to help each other better understand and accept their afflictions.

The aging population is also of concern to the Foundation because of the millions over 65 with arthritis, many of whom are immobilized by it. Because Osteoarthritis, or degenerative joint disease, is most often associated with the aging process, it has only recently been acknowledged <u>not</u> to be an inevitable aspect of aging, but rather an abnormal deterioration of joints caused by as yet unknown influences in the normal aging process, one of which may be related to occupational stresses.

Epidemiology, as was pointed out earlier, is an area in which we would welcome increased support. It is an important aspect of much of arthritis research, yet it is being seriously neglected.

Technology transfer can be carried out by a variety of groups but should not be assigned as a primary mission to NIH. Researchers, however, within the NIH system can certainly give attention to this area. To do so, however, would require special funding to be established to encourage this type of research. Research projects in technology transfer carried out by agencies other than NIH should be subjected to the same rigorous scientific review and study as are basic and clinical research.

New areas of investigation have to be approached in terms of precise answerable questions. It also has to be realized that the state of advances depends upon the current state of the art in the respective field of investigation. Too many studies in this area are either anecdotal, lack the application of scientific controls, or represent too small a patient population to be efficacious. Nevertheless, they are published as if they represented scientific evidence and thus persuade the public to often embark upon falacious therapeutic regimens, many of which can be deleterious to the patient's health or at the very least extremely costly with little or no long-lasting results. Thus, investigators need to be trained in approaches relative to the new fields.

Research in this area should be budgeted separately from basic and clinical research. A separate institute or agency may be set up to undertake this research.

Principle #5: "...HEW-supported research must be more effectively oriented to develop knowledge bases that support not just some but all the health missions of the Department -- prevention, delivery, regulation, standard-setting, and cost control."

It is difficult to gauge the need for a greater research capacity within HEW because of the extreme diffuseness (in distribution) of HEW's research activities. Nearly every health program has a research component. Before ascertaining the need for greater research capacity, it would perhaps be best to centralize the Department's research activities under a Coordinator. The relative effectiveness of research being carried out in these diverse areas could then be assessed and decisions taken at that time as to which appear to offer the best opportunities for arriving at answers to the nation's health problems. Too much of current HEW agency research only benefits in-house decisions and is not disseminated as widely as is needed to have an effect on major health policy questions.

We are obviously concerned that the health system is still organized for and resources still appear to be concentrated on acute rather than chronic diseases, and that the availability of research funds is predominantly contingent upon mortality rather than morbidity rates. We would submit that the economic cost factors of morbidity, such as those associated with arthritis, are much higher than those of mortality.

We are further discouraged that there is no relationship between what the government spends to ameliorate the economic impact of disease (Medicare, Medicaid, Social Security Disability Insurance, Supplemental Security Income, Veterans' Administration Disability and Compensation, etc.) vis-a-vis what it spends to find the causes and develop control programs for diseases and bad health habits (research, rehabilitation, public education, etc.). For example, Social Security currently pays out 15 percent of its Disability Insurance to arthritis victims and their families -- some \$2 billion per year, yet state vocational rehabilitation programs report that less than 2 percent of their patients are arthritics.

Academic Health Centers



Office of the President

September 1, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education & Welfare Hubert H. Humphrey Building 200 Independence Avenue, S.W. Washington, D. C. 20201

Dear Mr. Secretary:

On behalf of the Board of Directors of the Association for Academic Health Centers, I am pleased to respond to your invitation to submit our views on the principles which should guide the allocation of Federal monies in support of the nation's health research.

While the important issue of health research is deserving of a lengthy treatise, our response will be limited to a presentation of selected principles for your consideration. Some of our comments will, indeed, merely serve to reinforce a number of the important points contained in your excelent presentation of April 29, 1978.

- l. While we support the view that the nation's health research must be responsive to issues and illnesses which are currently compromising, the health and well-being of the citizenry, we strongly endorse your statement that a long-term investment must be committed to basic research. While you stated that "there must be freedom to pursue research topics that are not immediately relevant," we respectfully submit that mere freedom for coch pursuit does not adequately address the issue. Indeed, future strately must assure that both basic and more immediately relevant research be pursued. Such assurance will require a conscious decision to allocate a portion of total Federal dollars to basic research, thereby protecting those funds from the inevitable social and political pressures of the day.
- 2. We applaud your principle that attention must be directed to the development of future investigators. In the absence of a strategy of the type you are now requesting, training programs suffered early and disproportionate cut-backs during the past decade of fiscal constraints. We in academic health centers have observed this phenomenon with increasing concern and have been led to the view that training money will be a continuing victim of open competition for limited dollars. Accordingly, we urge that five-year funding strategy reflect a commitment to support of training and development of young investigators.
- 3. We wish to convey our strong support for preservation of the project grants mechanism for distributing research dollars. While there is a place for the contract grant mechanism, the trend to depend too heavily

The Honorable Joseph A. Califano, Jr. Page Two September 1, 1978

on this approach must be checked. The future will be best served by capitalizing upon the imagination and innovative strengths of the nation's biomedical research community.

- 4. In contemplating the future of the nation's health research efforts, we wish to state our unqualified view that the existing peer review mechanism should be maintained as an essential element in any system of Federal support.
- 5. The pool of the nation's research manpower now includes representatives of disciplines not traditionally identified with biomedical research. The research challenges of the future, however, will require contributions of those from a wide spectrum of professional disciplines. A strategy for the future allocation of Federal monies must include mechanisms which accommodate to the changing nature of the research community.
- 6. The development of the nation's current biomedical research capacity could not have been achieved without the commitment of large sums of money for the construction of physical facilities. As you so wisely described, the quality of physical plants and equipment has undergone serious deterioration. It is essential that plans for the future include appropriate programs for construction and renovation of research facilities.
- 7. As a principle to guide future strategy we wish to emphasize that the nation's health research efforts must not be compromised by the stifling effect of increasing Federal regulations. Bureaucratic excesses must not be permitted to divert money and time away from our health research efforts.
- 8. While we strongly support planning for the future, we caution against the development of plans which are so firmly established as to inhibit the ability for response to opportunities presently unforeseen. Flexibility to exploit a scientific "breakthrough" or pursue serendipitous discoveries must be preserved. It is recommended that a financial reserve for such purpose be included in a strategy for the future.

Thank you for your solicitation and consideration of the above comments. We applaud your efforts on behalf of the nation's health research endeavors. The Association for Academic Health Centers will be pleased to provide further assistance as you proceed with your important task.

Sincerely yours,

Merlin K. DuVal, M.D.

MKD/jmd



association of american medical colleges

JOHN A. D. COOPER, M.D., PH.D. PRESIDENT

August 2, 1978

202: 466-5175

Honorable Joseph A. Califano Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Joe:

This will acknowledge with our appreciation your letter of July 19 concerning the development in the Department of Health, Education and Welfare of a multi-year strategy to guide the allocation of government health research monies. The Association of American Medical Colleges has a major interest in any effort of this nature because, as you are aware, the academic medical centers are the largest single institutional component in the nation's health research effort. We are both grateful for the opportunity to participate in the development of the DHEW strategy and propose to cooperate with you and Don Fredrickson to the maximum extent possible.

In response to your invitation to comment on "--the principles that the Department should adopt to guide these hard choices," I am enclosing a copy of the policy statement on biomedical and behavioral research recently adopted by the Executive Council of the Association. A list of the distinguished individuals who drafted the statement is enclosed. While the goals enumerated in our document do not coincide completely with the principles you enunciated in your San Francisco speech, we believe there is sufficient convergence to make this document largely responsive to your request for comments by August 7.

I would like to add two observations to the material included in our policy statement. The first reemphasizes the importance of adequate support for fundamental research in all fields. Subsequent to the development of our document, it has become increasingly apparent that our nation is steadily

Page 2 - Honorable Joseph A. Califano August 2, 1978

losing ground to other scientifically and technologically advanced countries and faces the definite danger of being superceded in its worldwide leadership in that area. country has developed great economic strength as a result of our technology-oriented society and this deterioration of our position in international competition becomes an increasingly serious threat to our way of life. present superiority is, in large part, directly attributable to the strength of the nation's ability to produce and apply new knowledge. Regaining the lost impetus will be dependent on reinvigorating our basic research enterprise. It is also a fact that the strength, diversity, quality and productivity of that effort is heavily dependent on sizeable investments of funds from the Federal government. We are convinced that in the area of health, as in other scientifically based sectors of our national life, a reaffirmation in word and deed to this objective is a national imperative.

The second observation is, in fact, closely related to the first, but involves a specific item which, in hindsight, may be insufficiently stressed in the Association's policy statement. I refer to the considerations associated with the government's patent policy and the handling of information and documents which may impinge on patentability. William D. Carey, publisher of Science, has eloquently and cogently described the importance of a well considered patent policy in the editorial for the June 30, 1978 issue. Although he speaks to the generic context, the issues are similar for the biomedical field as for other areas of science and technology. In fact, the one landmark examination of government patent policy in the biomedical field provides ample evidence in support of the case Carey makes in his editorial. I refer to a Report to the Congress by the Comptroller General of the United States, entitled "Problem Areas Affecting Usefulness of Results of Government-Sponsored Research in Medicinal Chemistry, August 12, 1968. We would urge, therefore, that the development of the Department's multi-year strategy for biomedical research include specifically comments on an appropriate and effective patent policy. That consideration should also include recognition of the necessity of adequate protection of proprietary information, such as is contained in research grant protocols or applications, in order to protect possible patentable discoveries.

Page 3 - Honorable Joseph A. Califano August 2, 1978

Thank you again for your invitation to participate in this important endeavor. We shall look forward to receiving a copy of the "proposed principles" to be made available prior to the National Conference scheduled for October 3-4 as well as to other opportunities to join you and your colleagues as this effort develops.

Warm regards,

Sincerely,

John A. D. Cooper, M.D.

Enclosures

The AAMC policy on biomedical research was last formulated in 1971 (JME, August). In 1977 the Executive Council of the Association appreciated the fact that significant changes had occurred and continue to occur in the goals, environment and mechanisms of support of biomedical and behavioral research. In June, 1977, the Executive Council appointed an ad hoc committee to review its existing policy and to recommend needed revisons. The committee drafted a policy statement which was extensively discussed on January 18, 1978, at a special meeting of the Council of Academic Societies and revised according to suggestions received there, at a subsequent committee meeting, and during the 1978 Spring meetings of the Administrative Boards, Council of Deans, and Executive Council.

On June 22, 1978, the Executive Council of the Association of American Medical Colleges approved the following goals and recommendations as the AAMC policy for biomedical and behavioral research:

- GOAL 1: Emphasize that all levels of biomedical and behavioral research, including basic, applied, and targeted, are necessary.
- GOAL 2: Train a sufficient number and diversity of skilled investigators to conduct biomedical and behavioral research.
- GOAL 3: Develop effective public involvement in the formulation of research policy.
- GOAL 4: Strengthen the mechanisms of reviewing and coordinating research.
- GOAL 5: Improve the structure and function of the institutions which perform research and those which support research so as to promote the orderly transfer of research findings to patient care.
- GOAL 6: Assure adequate support for all aspects of the research process.



ASSOCIATION FOR CHILDREN WITH LEARNING DISABILITIES

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August 7, 1978

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MRS JEAN PETERSEN

Joseph A. Califano, Jr. Secretary, Department of Health, Education and Welfare 200 Independence Avenue, SW Washington, D.C. 20201

Dear Secretary Califano:

Thank you for your request to this organization for our views and suggestions on the principles that DHEW should adopt to support health research.

ACLD is a non-profit volunteer organization of 60,000 parents and prefessionals who are closely associated with learning disabled childrence hese are children who have near or above average intelligence, but who have a cerebral dysfunction which somehow affects their brain's ability to process information appropriately. During their school years their inability to learn is a symptom of their disability. Frequently, they have a high incidence of hyperactivity, poor impulse control and allergies. As they become teenagers poor logic and social ineptness are usually apparent.

The link between learning disabilities and juvenile delinquency has also become apparent, with reports such as that of GAO (GGD-76-97) dated March 4, 1977, which said that

One-fourth of the juvenile delinquents in institutions tested by GAO consultants had primary learning problems (learning disabilities). Whether these disabilities caused delinquency is uncertain; the question warrants further examination.

The Department of Health, Education, and Welfare should develop prevalence rates of children having learning disabilities, determine the resources needed to combat the problems, and develop procedures so that such children are adequately diagnosed and treated.

The same GAO study reported that another 51% of the juvenile delinquents had "secondary" learning problems. The "secondary" problems involved those who did not display the classic perception, integration and verbal expression problems, but were nevertheless underachievers and frequently had behavioral problems. Thus GAO found 77% of the delinquents studied had either primary or secondary learning problems.

Still more recently, in an ongoing \$2 million research effort funded by LEAA, ACLD and Creighton University researchers, working together, have found that 16% of all high school students had learning disabilities, and 32% of incarcerated youth had the problem.

The 1977 Edition of the Merc Manual, used nationwide by medical personnel, states that

Of the 51.5 million school-aged children in the USA, an estimated 5% to 15% (2.5 to 7.5 million) have some type of learning disorder.

Because a definite definition of learning disabilities has not yet been determined, incidence figures vary. But even if the incidence were only one-half the Merc figures, this is an epidemic!

In March, 1978 distinguished neuroscience researchers gathered in Kansas City for a two-day workshop sponsored jointly by NINCDS and ACLD. They arrived at a list of the 20 top research efforts needed in the LD field. This list of research priorities is in the process of being published, but the attached paper on "Areas of Research Needed in Learning/Behavioral Disorders" lists questions parents and professionals need researched today.

ACLD is publishing with the September/October 1978 issue of its national newsletter an 8-page "Research Update" on the neurobiological aspects of the dysfunction. A copy of the report on "The LD Child Grows Up", which is part of that Research Update, is attached. Note that many adults also have learning disabilities. The entire Update will be forwarded to you within a few days, as soon as it is off the press.

We believe that our Government, through research, <u>can reduce</u> (1) the heartache in the millions of families involved, (2) the welfare costs because of loss of productivity of so many of its citizens, (3) the cost of special education programs, and (4) the cost of judicial programs for crime and delinquency.

For young people experiencing an agony of learning and/or living, educational programs and parental understanding can help somewhat. However, prevention, treatment and cure will depend upon medical research in the neurosciences.

We do not believe you can find research in any other area that is so desperately needed and which holds so much promise for helping our nation.

Sincerely,

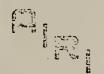
John A. Wacker, Chairman

ACLD Scientific Studies Committee

10848 Strait Lane Dallas, Texas 75229

cc: Alice Scogin, President, ACLD

Enclosures



September 22, 1978

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Dr. Donald S. Fredrickson Director Building 1, Room 124 National Institutes of Health Bethesda, Maryland 20014

Dear Dr. Fredrickson:

The following recommendations on Health Research Principles were unanimously approved at the Annual Meeting of the Association of Independent Research Institutes on September 15, 1978. I will be unable to attend the Conference on October 3-4 but Dr. Federico Welsch will present these recommendations and discuss them on behalf of AIRI.

- 1. Greater stability of support of biomedical research is urgently needed. This would require that NIH consider more carefully the effect funding in one year has on the commitment base in the next two or more years. Consideration should be given to funding more grants for periods longer than three years; reinstituting career awards and increasing the number of career development awards. Multi-year planning for research support can, in principle, help in reducing instability.
- 2. A substantially greater proportion of NIH funds should be used for funding <u>scientist-initiated</u> project grants (RO1's).
- 3. The peer review system is vital to a strong research effort and its functions should be made as effective as possible. The credentials of the applicant should be given more weight than the bulk of the application.
- 4. A continued supply of highly qualified trained scientists for the biomedical research interprise must be worked into a multi-year plan.

Sincerely yours,

Lewis L. Coriell, M.D., Ph.D.
President

LLC:dnm cc: Dr. Welsch

Association of Schools of Public Health

1500 Wilson Boulevard Suite 807 Arlington, Virginia 22209

August 4, 1978

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Secretary Joseph A. Califano
Department of Health, Education and Welfare
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Califano:

The Association of Schools of Public Health is pleased to respond to your request for comments on the proposed multi-year strategy for health research. Enclosed is our initial response which focuses particularly on principles four and five. We see these as necessary emphasis to give the new policy direction and substance.

We also emphasize research training since manpower development, which increases the supply of young investigators, is an essential ingredient in any long range research strategy.

We applaud your initiative and look forward to continuing involvement in the formation of this policy development so curcial to the nation's health.

Sincerely yours,

Jerrold M. Michael

Jerrold M. Michael President, ASPH

cc: Donald S. Fredrickson

Joseph G. Perpich

Executive Committee, ASPH

Comments On
HEW Multi-Year Strate For
Support of Health Research

from the Association of Schools of Public Health

The Association of Schools of Public Health represents the twenty accredited Schools of Public Health located in some of the largest and best research universities within the United States. In these settings, research is an important goal and a number of schools of public health operate with a research budget which is, on a per capita basis, larger than that of any other school or college within their respective universities. Thus, the commitment of these institutions to research, though often poorly understood, is extensive and absolute. This commitment in part arises from the fact that students are mainly at the graduate level and the faculty come from a research background.

The nature of this research ranges from the basic health sciences of biostatistics, epidemiology, and the bahavioral sciences to applied research into the organization, delivery, efficiency and effectiveness of personal health services and the investigation of environmental factors impacting on human health. Organizational strength in biostatistics, epidemiology, health services, and environmental health is mandated in these schools by the guidelines of the accrediting agency.

The U.S. commitment to biomedical research has traditionally been strong, and all Americans should recognize that strength and urge that it be maintained. In terms of total dollar investment, this research has been concentrated within the nation's medical schools and has, therefore, emphasized the basic medical sciences (microbiology, anatomy, biochemistry, physiology, pharmacology, and pathology) and the clinical sciences (both medical and surgical). There has, in the past, been little emphasis within medical schools on biostatistics, epidemiology, health services, or environmental health. An exception must be made for the relatively few medical school departments of preventive medicine large enough to mount a substantial research program in one or more of these areas. These latter departments often find themselves in competition with their larger and more affluent sister departments emphasizing research in the basic and clinical sciences.

The schools of public health applaud and support the Administrations effort to develop a better strategy to guide the allocation of the federal research dollar. A multi-year plan for health research

will help stabilize the fluctuations in annual funding levels which make rational planning so difficult. A strategy for health research based on a systematic and comprehensive assessment of research and health needs is long overdue.

The first three principles are important and indisputable, i.e. to maintain and enhance support for fundamental research into biology and behavior, to assure ample opportunities for young investigators, and to accompany basic research with vigorous, thoughtful and appropriate interdisciplinary application.

We further stress the importance of the forth and fifth principles which will provide direction and orientation to the research effort. Government supported research must have a strong orientation toward improving the quality of the nation's health and the effectiveness of its health services, and must be more effectively oriented toward developing knowledge bases that support prevention, delivery, regulation, standard setting and cost control.

We are encouraged by the spotlight Secretary Califano placed on the schools of public health and the partnership envisioned between schools of public health and other research institutions. This emphasis highlights the need for increased research in biostatistics, epidemiology, health behavior, health services, environmental health and nutrition. Developments in these areas should become a national priority.

If such a priority is established, several steps will be needed to provide for it:

- 1) Institutional and project research within the schools of public health should be increased by larger allocations to the areas of biostatistics, epidemiology, behavioral sciences, health services, environmental health and nutrition. These allocations should be awarded, in keeping with long established and proven tradition, on a competitive basis and subjected to rigorous peer review.
- Support for research training in these areas should be increased in order to guarantee an undiminished flow of young investigators entering the pool of trained research workers. This cannot be over emphasized since policies of recent administrations have not encouraged the preparation of research scientists in any area, certainly not these areas.
- 3) Departments of preventive medicine and community health within medical schools should be stimulated to grow and to deepen their research programs in these critical fields.

A plan to implement the fifth principle concerning prevention, delivery, regulation, standard setting and cost control should end

the platitudes about the importance of prevention to general health and cost containment. Unfortunately hard data to enable us to go beyond rhetoric is limited and fragmentary where it exists at all. By federal policy, research on the cost implications of preventive strategies should be developed and supported. Only a clearly stated policy and a well-supported federal program can provide the necessary growth spurt to encourage young investigators to enter this work and to encourage well-established investigators to move into this field, and to elevate this investigative area to its appropriate priority level.

The impact of the environment on health and disease and the cost of correcting the resultant health problems is only poorly understood in spite of decades of emphasis. New research methodologies must be developed and it will fall largely to the fields of biostatistics and epidemiology to develop these techniques. While the impact of environment on health has been well documented in certain acute episodes, the general effect of the environment on health, whether by environmental disasters such as the PBB tragedy in Michigan, the kepone exposures in the Eastern states, the role of slow viruses or the impact of low level atmospheric pollutants is only poorly understood in rigorous, quantitative, scientific terms. Again, a federal initiative to correct this important gap in fundamental knowledge must be established.

The nation's schools of public health currently possess the capacity to absorb a greater emphasis on the five critical research areas emphasized in this statement. This is true at least on the short term. Other universities have expressed an interest in establishing schools of public health, and we anticipate that several new schools will be organized and accredited within the next several years. Furthermore, a major undeveloped capacity exists within the nation's medical schools. If these institutions and their administrative leaders will become motivated to support these five critical investigative areas, further capacities can be developed within these settings. If, however, the medical schools continue to emphasize mainly, perhaps even only, the traditional basic medical sciences and clinical sciences, then future contributions to sound investigative work in preventive medicine and the basic and applied public health sciences will continue to be limited and fragmented. Policymakers should watch with interest the reaction of the nation's medical schools to any new initiatives designed to improve investigation in these fields.

A word of caution is in order regarding reallocation. Reallocation of limited health resources is needed in specific instances but this is only a partial solution. An unfortunate tendency exists within the federal government at present to impose unrealistic ceilings on the nation's health research capability. We are calling attention in this statement to a lack of historical emphasis on several critical fields of health research. This lack

ASSOCIATION OF SLEEP DISORDERS CENTERS

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William C. Dement, M.D., Ph.D. Director, Sleep Disorders Clinic and Laboratory Professor of Psychiatry Stanford University School of Medicine

August 9, 1978

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University of Pittsburgh
School of Medicine

Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D. C. 20201

Dear Secretary Califano:

I am sending this letter as one spokesman for people to practice sleep disorders medicine and who do research on basic sleep mechanisms and clinical sleep disorders.

- 1. My first suggestion is to request that this health area have a specific representation in the HEW organization. Although sleep professionals are responsible for sleep-related health problems affecting 40 million Americans, the field does not have a clear place or priority in the ADAMHA or NIH hierarchy. Therefore, problems of totally disabling illnesses like narcolepsy, fatal illnesses like sleep apnea syndromes, the abuse of sedative hypnotics, and a host of other problems are continually shunted aside. Further, there is no federal encouragement of education about the physiology of sleep and about clinical sleep disorders and proper use of hypnotics in our medical schools. As a result, physicians are graduating today who are totally ignorant and inept in these important areas.
- 2. The second suggestion is to eliminate waste. In research, accountability is most easily accomplished by scruitinizing scientific productivity. The enormous overhead and hoards of accountants checking and controlling every expenditure of principal investigators is horribly inefficient. The very short time commitments to research programs also generates great inefficiency.

- 3. Something must be done to diffuse the intensity and competitiveness of peer review. I believe the appointment of an ombudsman was one of the suggestions made by Director Fredrickson's task force and was one suggestion which is not intended to be implemented. Though complex, some sort of appeal mechanism would be enormously helpful.
- 4. Finally, the way in which overall health care and research priorities are established is unclear. One factor that should continue to be taken into account is the prevalence and costs of a disease. The hue and cry against disease-oriented research by basic scientists is obviously motivated by self-interest. The real question is the level of basic research that is most likely to bring about rapid improvement in the situation of the patient. Basic research can still be assigned a relevance. For example, work on the molecular mechanisms of kidney tubular function will probably improve sooner or later the lot of sufferers of kidney disease. On the other hand, the greatest need of hundreds of thousands of patients with narcolepsy is for the first controlled clinical trial of a potential chemotherapeutic agent to be conducted.

I would like a copy of the set of principles sent to me at the following address: Association of Sleep Disorders Centers, TD 114, Stanford University School of Medicine, Stanford, California 94305. Thank you very much.

Sincerely,

William C. Dement, M.D., Ph.D.

President

Association of Sleep Disorders Centers

WCD:1h



THE UNIVERSATY OF ARIZONA

HEALTH SCIENCLS CENTER TUCSON, ARIZONA 85727

COLLEGE OF MEDICINE
DEPARTMENT OF ANESTHESIOLOGY

MEMORANDUM TO: The Honorable Secretary Joseph A. Califano

SUBJECT: HEW multi-year strategy for support for Health Research

Dear Mr. Califano:

As President of the organization, I represent the 300 members of the Association of University Anesthesiologists, the voice of this academic discipline in American Medical Education. I am writing you concerning Health Research and your request to input to DHEW.

Obviously from our parochial point of view, be it altruistic or self-motivated, we cannot argue against the concept of more funds for basic biomedical research. Those of us in our rather undermanned specialty of anesthesiology are critically aware of the shortage of young men and women entering careers into anesthesiology teaching and research. Shortage of grant funds

and fellow-ships is the main reason for this.

Yet anesthesiology, somewhat of a "sleeper" that does not catch the headlines or the public attention of heart disease, cancer etc., still represents a public health problem of large magnitude. There are 25,000,000 anesthetics administered to U.S. citizens annually. Mortality rate is 1:3,000 adminisrations giving us at least 8,000 avoidable deaths. Research is needed in epidemiology, safety, delayed toxicity, and pharmocology of this public health problem.

In addition to its primary and conventional role in the operating and obstetric suite, many other public health problems

fall within the purview of the field.

Chronic pain (low back, cancer pain, headaches, neuritis, etc.) is an economically devastating cause of disability in young and middle aged Americans. Less than 50% of industrial low back injuries ever return to gainful occupations. Although no absolute statistics are available, the economic loss and personal tragedy of these problems coupled with excessive disability and litigation probably supercedes the economic devastation to this country of cancer. Anesthesiologists have long been in the forefront of development of multidisciplinary pain clinics. The need for Regional Pain Treatment and Research Centers is great. Emphasis must be placed on these from a point of view of rehabilitation, treatment, and research. Yet funding

in the area is miniscule.

Cost effectiveness of intensive care units is another area of great public need. Development of new anesthetic drugs and tranquilizers is paramount to decrease anesthetic mortality.

Obviously, I speak somewhat as a zealot, but my experience not only as a physician-scientist and teacher, but also as a former rural general practicioner compèl me to write to you in the name of our association expressing our views and requesting that funding in the area be increased, not cut.

Sincerely,

Professor and Head,

Dept. of Anesthesiology Dept. President Association of University Anesthetists

mb



Ifr Joseph A. Califano, Jr.
Department of Health, Education and Welfare
Washington, D.C. 20201
U.S.A.

Dear Mr Califano,

Thank you for your letter of July 19, 1978, that unfortunately only reached me recently due to being sent by surface mail and then not forwarded to me in Stockholm from Geneva.

Your letter and the copy of your remarks in San Francisco raises most interesting and timely questions.

Since a few years I am getting more and more involved in the increasing health research efforts of WHO and am therefore very concerned with research developments in the member states and the possibilities that an increasing part of these efforts in the industrialized countries might be devoted to problems of central importance to the health of the population in the developing countries.

It is certainly true that much progress could rapidly be made in developing countries by political decisions to reallocate more funds to rural developmental and educational efforts with excisting knowledge and techniques. - However, in many fields especially related to infectious and parasitic tropical diseases, our knowledge of prevention and therapy is very unsatisfactory and on a very much lower level than that of most diseases in industrialized countries.

Even if it is of prime importance that efforts should be concentrated on a wider application and utilization of excisting knowledge, it is imperative that research is intensified especially in the fields of parasitic diseases and in gastroenterology - children diarrhoea still bring the most common cause of death in underprivileged populations

As our basic knowledge is insufficient - and development of new therapeutic drugs based on new knowledge takes 5-3 years it is clear that these efforts of broadening our basic knowledge in these fields should be intensified immediately.

The powerful pharmaceutical industry of the US must also be involved in this work. It is therefore necessary to find suitable forms for first dipation (contracts etc) as the ordinary market forces are not operative when it comes to developing and supplying drugs to developing countries.



The initiative of the Institute of Medicine to arrange a conference to discuss how this could be done is therefore very important.

A very modest increase in the percentage of NIH funds spent on research efforts in these areas - preferably in some coordination with the efforts of the Tropical Disease Programs of WHO, UNDP and the World Bank would be of decisive importance.

My opinions have been elaborated in the enclosed reprints from which I cite.

"No nation has contributed more to the support of biomedical research in other countries than the United States, either through private foundations or with federal funds. It is therefore of vital importance that the American experience and scientific expertise be fully utilized in this work, and that the large bilateral programs of the United States continue to be generously complemented by increasing support for these multilateral efforts, together with those of many other nations.

The large investment of the United States in biomedical research during the second century of its existence may well turn out to be a decisive factor in the effort to bring the health care of the majority of the worlds population to an acceptable level - a problem that must find its solution long before the end of the third century of the American republic."

Cooperation and joint efforts in the fields of health is probably the most effective way of improving and increasing friendly and rational cooperation between industrialized and developing countries.

Sincerely yours,

Sune Bergström

Blue Cross Association Blue Shield Association



Walter J McNerney President 840 North Lake Shore Drive Chicago, Illinois 60611 312/440-6010

August 2, 1978

Dear Mr. Secretary:

Thank you for your letter of July 19, 1978, concerning the development of a multiyear strategy to guide the allocation of federal health research expenditures. I offer the following thoughts:

- 1. A broad, multiyear health research strategy is badly needed. The process which you outline for developing this strategy appears appropriate and reasonable.
- 2. We need to recognize that there is no formula that can determine the exact or optimum amount to invest in health research. Recognition should also be made of the impact that changes in support levels will have on the productivity of health research.
 - In consideration of these facts, the strategy should call for a broad-based political decision to establish prospectively a multi-year allocation for federal health research expenditures. Also, target percentage allocations among basic and applied biomedical and health services research should be set.
- 3. The health research strategy should support an overall national health strategy or policy. The health research strategy should call for continued contribution of information needed to develop/refine national health policy. The strategy should require that we be more end results oriented. Research efforts funded should explicitly and directly support achievement of a policy goal.

For fundamental research, this implies that every research effort make a contribution to needed basic knowledge and understanding. This posture would foster greater productivity in the research establishment. For applied biomedical and health services research, each effort (or at least the theoretical track on which an effort is founded) should lead to decreased mortality, decreased morbidity, lower cost, or a better "quality" of life for as large a share of the population as is possible.

Were such a health research strategy working today, I believe greater emphasis would appropriately be placed on studying the areas of environment, genetics, lifestyle, and nutrition; on learning how to cope with diseases of middle and advanced age in the broad context of community life; and on determining the value of various forms of new technology and procedures through controlled field trials.

- 4. The health research strategy should provide explicit criteria to guide priority determinations among competing alternative expenditures within a given type of research. The use of these criteria should lead to the selection of the array of research projects which should have the greatest end result. For example, within the health services research area, for the near term (five years), cost containment potential could be a discriminating variable in choosing between two projects impacting on a policy goal.
- 5. In addition to providing resource allocation direction, the health research strategy should call for the establishment of a monitoring function, presumably within the National Institutes of Health, that would ensure that agency operations and allocations remain consistent with the policy guidance provided by the strategy.

Thank you for the opportunity to comment. I would appreciate receiving and reviewing your proposed principles which will be presented at the October 3-4 conference.

Sincerely yours

Walter J. McNerney

Honorable Joseph A. Califano, Jr. Secretary Department of Health, Education, and Welfare Washington, D.C. 20201

WJM:lie

Dear Secretary Califano,

I read with interest yaur memarks delivered April 29, 1978 before the annual meeting of the American Eederation for Clinical Research and also your memorandum dated July 19, 1978 me: HEW Multi-Year Strategy for Support for Health Research.

History has shown it is possible for a government to solve technical problems, like making an atomic bomb that works, by throwing people and money at the problems. Disease problems are only occasionally solved in this manner.

The problems of metabolic toxemia of late pregnancy, abruptio placentae, prematurity, low birth weight, congenitally damaged children, severe maternal, fetal and neonatal infections, maternal, fetal and neonatal mortality, have received considerable attention from the N.I.H., especially the NICHD, over the last 25 years...with practically no concrete solutions regarding the PREVENTION of these problems. The incidences of low birth weight and premature labor and delivery have increased here in the U.S.A. since the early 1950's among women in all economic classes. This epidemic of low birth weight babies suffering congenital defects continues unabated toda; in our nation but not in most other industrialized nations.

My own disappointing experiences with the N.I.H. have convinced mc that the present experts will never bring to the Congress and to the U.S. American people truly scientific answers to the problems of PREVENTION of these pregnancy diseases. Why not? Because they have rigidly repressed recognition of the role of malnutrition in the etiology of human reproductive casualty; much of this pregnancy malnutrition here in the U.S.A. has been for decades, and continues to be today, iatrogenic in etiology.

Under total domination of the private drug industry, and more recently of the private electronics and hospital industries, maternal-fetal and neonatal "health" activities have centered on the <u>crisis care of diseases</u>. First with drugs, low calorie, low salt diets, blind weight limitations, and now with sophisticated electronic monitoring devices, biochemical testing, amniocentesis, sonar, etc., our medical professionals have attacked these diseases with costly zeal: Prevention in this field when linked with applied science (physiology and nutrition) is scorned as "faddism. The many valid clinical and epidemiological studies linking these problems with malnutrition during pregnancy and abuse of drugs like amphetamines and sodium diuretics are simply ignored...like our testimony to the FDA, Bureau of Drugs, OB-GYN Advisory Committee, on July 17, 1975 regarding use of low calorie, low sodium diets and sodium diuretics in metabolic toxemia of late pregnancy.

We have recently analyzed over 300 scientific studies in this field which support our basic thesis that no meaningful HEALTH MODEL can be developed in this field which excludes applied physiology and nutrition on the clinical level. I urge you and H.E.W. to examine these facts:

Sincerely yours, Tom Brewer, M.D.

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Xc: Senators Cranston, Percy, Dr. Donald Kennedy

CHAIRMAN.
TOM BANE
ASSEMBLYMAN.
FORTIETH DISTRICT

SENIOR CONSULTANT
MARLENE ROTHSTEIN

SACRAMENTO ADDRESS STATE CAPITOL SACRAMENTO 95814 PHONE: (916) 445-9134

California Legislature

ASSEMBLY SPLEGH COMMITTEE ON GENETIC DISEASES MEMBERS
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BARRY KEENE
BRUCE NESTANDE
HERSCHEL ROSENTHAL
BILL THOMAS
FRANK VICENCIA



August 15, 1978

Hon. Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Washington, D. C. 20201

Dear Mr. Secretary:

The views, perspectives and concerns of the California State Assembly Select Committee on Genetic Diseases toward development of a strategy to guide health research activities in the Department of Health, Education and Welfare in the coming five years are necessarily limited. Our suggestions will be developed within the parameters of our committee function.

Our emphasis has been in the area of basic research, an emphasis we feel should be continued, strengthened and expanded beyond its current level at the National Institutes of Health, through HEW.

Basic research developments are the newest and potentially most promising. As a consequence, gains within basic research may prove to be a long-range cost effective approach. The attendant moral issues, possibly resultant from progress in the area of basic research, must necessarily be addressed by interdisciplinary approaches on a concurrent level. It is generally recognized that the goal of eradication of disease, control and treatment of extant disease, and cost effective health care delivery for all citizens may not be realistic with limited health research dollars. It would appear that the greatest emphasis must retain in basic research categories, with definition established as need indicated rather than "popularity".

Health care delivery should be considered within the context of legislation rather than HEW direction. If this direction is taken, health care delivery systems may not require consideration when establishing long-range plans for NIH.

Among these plans should be the preparation of interdisciplinary reviews to synthesize current knowledge and obviate the necessity for innumeral () to unreadable and unread) journals.

Telephonic data banks and informational open lines could be considered as replacement for endless symposia.

Utilization of the National Academy of Sciences as an interdisciplinary group to collect and inform all the disciplines regarding advancement (with elimination of narrow specialties) and emphasis upon implications for all fields should be a priority item.

Development and funding of more five-year to lifetime research professors engaged in pure research should also be considered as a priority.

Further, the added disciplines covering individual_responsibility for health maintenance should not be obscured. The necessity for planning integration of the field appears to be on the increase.

The above, in brief, represents some current directional thought.

It would be a privilege to consult further and to participate at all levels of the decision-making process. Your solicitation of views is appreciated.

Respectfully.

Dr. Marlene Rothstein Senior Consultant

MR:sc

The Children's Hospital Research Foundation Elland & Bethesda Ave. Cincinnati, Ohio 45229 Department of Pedieses College of Medicine University of Cincinnati

August 4, 1978

Mr. Joseph Califano Secretary of Health, Education and Welfare Department of Health, Education and Welfare 330 C Street, S.W. Washington, D.C. 20201

Dear Mr. Califano:

As you requested, I am sending you my views and suggestions concerning the development of a set of proposed principles for the HEW Multi-Year Strategy for Support for Health Research.

The best, most up-to-date physicians cannot deliver <u>new</u> health services about prevention, early diagnosis, or curative therapy until research has uncovered them. Governments cannot make sound policy decisions concerning health matters until research has uncovered the scientific basis for such decisions. Biological research even played a major role in making possible the major sociological change of this century, the emancipation of women from the necessity of devoting all their adult years to childbearing and child rearing in order to produce a sufficient number of survivors for family and wage earning purposes.

We need more advocates for infants and children. Infants, children and adolescents constitute over one-third of the population. Only by preventing deaths or disabilities in these age groups can one preserve all the working years, the tax paying years, and homemaking years to the benefit of themselves, to their families, and to society. For both humanitarian and national economic reasons, all of us should advocate more support to discover new biomedical information about unconquered pediatric disorders in order to: eliminate or prevent illnesses; devise treatments for currently untreatable diseases; improve and simplify available management for patients. The cost to the nation of specific diseases is a function of not only the number of cases, but also the duration of the disability influencing the wages lost and the expenses of care for the individual. Several cost analyses by Fudenberg, Stickle, McCory, and others have shown that death and disability in childhood cause a far greater number of life years lost and earnings lost than the corresponding losses from heart disease, cancer, and stroke combined. In Cincinnati, William Cooper Procter's investment in the Children's Hospital Research Foundation has made it possible for many more children to be healthy in the United States and throughout the whole world, than, if instead, he had devoted the same number of dollars to the care of children in community clinics and as patients in hospitals. No state can afford the enormous burden of caring for deformed, apathetic, stunted children who then become inadequate, unfulfilled adults, dissatisfied with society.

A second need is to influence the decision makers in congress and in HEW to appreciate the far greater benefit and cost-effectiveness derived from basic, unrestricted research as opposed to applied, targeted studies directed toward a specific

ADDLESCENT CLINIC: CHILDREN'S DENTAL CARE FOUNDATION CHILDREN'S HOSPITAL DISCUMPERS CONVALESCENT HOSPITAL FOR CHILDREN UNITED CEREBRAL PALSY OF CINCINATION OF CINCINATION

objective. Many individuals have a confused, distorted image of what science can accomplish as a result of the "Manhatten Project" and the "Man-on-the Moon Space Program." It is not appreciated that both of these were directed, applied research efforts that succeeded only because basic research already had produced the fundamental knowledge essential for them. This knowledge came from scientists doing basic studies in laboratories in many parts of the world over scores of years. These basic endeavors had not been supported by the Manhatten nor Space Programs. Those responsible for the nation's well-being must bolster support for basic research. Renowned scientists, from Karl Compton and Vannevar Bush in the 1930's to Kornberg, Comroe and Dripps in 1976, have examined how scientific advances are generated. All demonstrated the greater payoff from basic research.

Basic research is a persistent effort to make an original discovery; that is, to uncover something previously unknown. By definition, if the findings are truly new, they are unknown in advance. New discoveries are commonly at variance with accepted ideas and thus, at first, may be rejected even by the scientific community. Such investigations often are deemed to be frivolous, wasteful exercises by those controlling research monies. Ideas for basic research originate with creative investigators. Committees cannot formulate the ideas nor can they accurately judge the plans for conducting such research. Until some pilot studies have been accomplished, even investigators within the institution have difficulty in assessing the merits of truly innovative ideas.

The most effective mechanism of support is to provide proven university departments and successful research foundations with sufficient funds to allow their established scientists or promising young research trainees to carry out pilot experiments or to follow-up new leads that have arisen during the course of other investigations. What is needed is more funds distributed in a manner similar to Biomedical Research Support Grants. A system of decentralized grant making, based on review by institutional peers, and allowing for great flexibility to follow up a new observation of importance when it occurs, promotes and speeds up basic research. Then these preliminary observations can be formulated into basic research grant proposals to be funded via a competitive peer review system. Such a system will inevitably increase discoveries upon which applied research has to be built.

The uncertainties of support, with higher and higher proportions of "approved but not funded" grant requests, means that highly capable scientists are being kept out of the laboratories more and more to write grant applications, renewal requests, and multiple progress reports. The time spent per investigator on these non-research activities has increased manyfold during the last ten years, to the detriment of new discoveries through basic, unfettered research.

An additional critical area is the support of trainees in research. Highly relevant to this subject is the sociological review in 1967 pointing out that out of the fifty-five American Nobel Laureates, thirty-four worked as young men under a total of forty-six Nobel Prize winners. A study at our College of Medicine likewise shows that investigators with a background of research training are more than three times as apt to make important biomedical contributions than those without specific research training. To move forward in the future, it is evident that young people must be trained now in basic research skills. Stipends and modest "starter" grants for such individuals are sorely needed.

I would appreciate it if a copy of the proposed principles to be presented at a

National Conference on October 3-4 could be sent to me for review.

Cordially,

2. I. Small

Edward L. Pratt, M.D.

Director,

Children's Hospital Research Foundation;

Chairman,

Department of Pediatrics

ELP:mjo

Citizens' Committee for the Conquest of Cancer

7159 South Franklin Way, Littleton, Colorado 80122

Co-Founder SIDNEY FARBER, M.D. (1903-1973)

Co-Chairpersons EMERSON FOOTE SOLOMON GARB, M.D KAY MANSOLILL

August 14, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, DC 20201

Dear Mr. Califano,

I welcome your initiative in seeking a multi-year strategy to allocate government health research dollars, and your willingness to seek the advice of the individuals and organizations active in the health field. Here are my views and suggestions on the principles to be followed.

1. Public Representation on All Primary Decision Making Bodies.

The public must have an equal voice in the Advisory Councils to each Institute. Half of each advisory board should be laypersons, who are legitimate representatives of those with the greatest stake in the subject. This excludes any chosen by the Director of the Institute or any other government official, or representatives of so-called "public interest" groups who have no identifiable public base or accountability.

The proper public representatives on the advisory councils should come from the non-salaried volunteers who staff our great voluntary health groups. For example, the two million volunteers of the American Cancer Society are the primary representatives of the public and the consumer in relation to cancer. Most of them have either had cancer themselves, or have or had close relatives with cancer. Other groups from whom lay members of the NCAB could be chosen include the Leukemia Society, the Candlelighters, Citizens' Committee for the Conquest of Cancer, and the National Cancer Petition.

For the other institutes, lay members should be chosen from such public groups as the American Heart Association, Citizens for the Conquest of High Blood Pressure, Hemophilia Association, American Diabetes Association, Juvenile Diabetes Foundation, Cystic Fibrosis Foundation, The Muscular Dystrophy Association, The Society for Autistic Children, etc. Each of these organizations is a democratic group of concerned citizens, By their volunteering, their interest and their contributions, they have earned this right.

2. Balance between Basic and Applied Research.

The nation needs both basic and applied research. Unfortunately, for years, applied clinical research was members by NIH, and now that the pendulum is swinging the other way, was no researchers are understandably concerned.

Mr. Califano August 14, 1978 page 2

Entirely too much energy is being spent in arguments and squabbles over which should get more funds each year. I suggest that each Institute budget 50% for basic research and 50% for clinical and related preclinical studies such as development of new drugs. I would rely on the public representatives on the Advisory Boards to monitor compliance. This arrangement would be fair, acceptable to the general public, and should reduce the continual bickering and squabbling over basic vs. clinical studies.

3. <u>Uniform, Fair Overhead (Indirect Cost Rates)</u> Should Be Applied to All Grantee Institutions.

Each year, overhead rates rise, and the disparity grows. When overhead was a uniform 20% of total direct costs, there were more good grant applications than could be funded. Now, overhead rates vary from about 20% of total direct costs to over 75% of total direct costs. The wealthier institutions get the highest rates. This not only wastes about \$150 million per year, but prompts some university officials to pressure scientists to get grants for the sake of the lucrative indirect costs. Today indirect cost reimbursement is no longer based on true incremental costs of the research but on the fallacious notion that if a university scientist gets a research grant, the public has an obligation to pay part of the salaries of the University President, Vice-President, Chancellors, Deans, Secretaries, etc.

4. Research Missions Should be Consolidated in the Institute Most Capable of Carrying Them Out.

As things stand now, it is possible for a chemical to be tested by the Cancer Institute for carcinogenesis, by the Heart Institute for cardiac effects, by the Eye Institute for effects on vision, etc. Instead, I recommend that all testing of chemicals for toxicity be consolidated in the National Institute for Environmental Health Sciences.

5.

I have left to the last the most important point. We must allocate to health research a yearly amount consistent with the interest of the American people in maintaining their health and fighting disease. It is a national disgrace that in fiscal 1979 this nation will spend over \$4 billion on space research and less than \$3 billion for all of the National Institutes of Health. To how many Americans is the conquest of cancer, heart disease, hypertension, diabetes, cystic fibrosis, muscular dystrophy, mental illness, blindness, arthritis, and other serious illnesses less important than space research? Until the national budget is brought into some reasonable balance, with more funds going to NIH than to the space agency, we cannot accept any limitation on NIH funding. All the institutes in NIH are seriously underfunded in relation to their mission and to the expectations of the American people. We must not be diverted into a discussion of how to divide a totally inadequate amount, but instead must concentrate on finding out why the total amount is still inadequate and what we can do to improve it.

Mr. Califano August 14, 1978 page 3

Your initiative in seeking a national conference on the vital issue of health is both wise and timely. I would like to participate in the October conference and would appreciate your sending me a copy of the principles to be discussed.

Yours truly,

Solomon Garb, M.D.

SG/gr

cc: Interested Senators, Congressmen and Colleagues

THE COMMONWEALTH FRIND

HARKNESS HOUSE

I EAST SEVENTY-FIFTH STREET

NEW YORK, N.Y. 10021

[212] 535-0400

CARLETON B. CHAPMAN, M.D.

10 August 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education, and Welfare Washington, D. C. 20201

My dear Mr. Secretary:

This is in reply to your letter of 19 July addressed to the Chairman of the Board of The Commonwealth Fund, a private foundation, with which was enclosed a copy of your address to the American Federation for Clinical Research delivered on 29 April 1978. Our views are set out below and we have underlined the ones we consider to be most important.

The Commonwealth Fund, like many other private foundations, supported basic biomedical research for many years but, like most other foundations, withdrew from the field with the rapid expansion of the research-support programs of the National Institutes of Health in the late forties and fifties. It was the Fund's view at the time that it should seek other areas that were less well supported and it chose medical education. Its emphasis was on pre-M.D. curricular development in the medical schools themselves, rather than on premedical or post-M.D. education and training. But our contacts with the N.I.H. have remained close and cordial to the present time.

We are, of course, very familiar with the currents of criticism that grew up concerning the N.I.H. and its programs. On balance, however, we consider the public funds expended through the N.I.H. very well directed and regard its Study Section and Council mechanisms as an exemplary means of allocating public funds for technical purposes in the public interest. We take issue, however, with the politicization of the process although not with the principle of public representation on N.I.H. Councils.

We also took note, some years ago, of the imbalance that grew up between support for research and support for education and, to the except a form in the four primited funds allowed, attempted to correct the impalance.

With reference to the Five-Year Strategy for Basic Health Research, we recognize the need to redress prior imbalances while preserving the extremely positive accomplishments and influences the N.I.H. have had on our national life. With this caveat, we think the Strategy makes véry good sense.

As for the five principles that underlie the Strategy, I shall omit comment on the first three since, as you say, they are non-controversial. Number four, done right, is in our minds also non-controversial. It recognizes that not all the answers needed to improve the Nation's health and health services are to be reached in basic science laboratories, a fact which some basic scientists are still unable to accept but which we accept in principle. The danger is that principle Number Four may lead to over-investment in the short-term effort at the expense of the long-term. If the latter can be appropriately protected, we find the fourth principle perfectly reasonable.

The fifth principle seems to us to involve matters that, although of fundamental importance to the Nation, may well lie outside the existing mission of the N.I.H. themselves. We have never been quite sure just where research on patterns of health-care delivery, regulation of quality and services and the related setting of standards, and cost control really In our own view, experiments in health-care delivery are the most difficult not only to place but also to carry out properly. Very few universities that possess medical schools are capable of mounting them and most should not try to do so. There are, however, a few exceptions. They should be encouraged, even challenged, to enter the field and should be well supported with federal funds if they undertake the effort. Even so, their primary focus might well be on the impact of new systems for health-care delivery on the clinical training of health professionals, including physicians, only secondarily on socio-economic The N.I.H. would be the granting agency but not the factors. prime mover. In any event, we believe the notion that a thousand such experiments are necessarily better and more promising than a few critical and well-planned ones is utterly fallacious.

As for standard-setting for professional services, this is a matter which is the clear obligation of the professions themselves although, in a historical sense, they have neglected the obligation very badly indeed. We recognize that the PSRO law is designed to bring them into the activity more fully but we doubt that in its present form the law will prove to be more than partly successful. We doubt, however, that the N.I.H. has any role to play in this difficult business, with which the matter of cost control is so intimately bound up.

Probably the most important potential of the Five-Year Strategy is the hope that it will lend coherence to, and reduce uncertainty concerning, the fundamental programs of the N.I.H. This, to our minds, is a strong recommendation for it. The maintenance of the health of the N.I.H. themselves is critical. As a private funding agency, we whole-heartedly approve of public funding for specified health purposes via N.I.H. mechanisms. In our minds, in fact, the characteristically candid and cordial interaction between many of the private foundations and the N.I.H. is an example of pluralism at its very best.

We should like, Mr. Secretary, to lend any assistance open to us in these very important connections and will respond at any time to further inquiry.

Yours sincerely,

Carleton B. Chapman, M.D.

President

CBC:srp



The Commonwealth of Massachusetts Department of Mental Hessis

160 North Washington Street, Boston, Mass. 02114

August 29, 1978

Joseph Califano, Jr., Secretary Department of Health, Education & Welfare Washington, D.C.

Dear Mr. Califano:

I am writing in response to your memorandum on the allocation of limited government health research funds.

The problem of the mentally disabled and mentally ill is one of the major areas of health care where more research and funds are needed. Mental illness can affect all people - young and old. Effective treatment and better understanding of the underlying biochemistry is essential. Improvements in care and understanding of mental patients can convert many young people from lifelong burdens on society to useful citizens. Currently, annual expenditure for mental illness is more than \$50 billion dollars. Clearly this area is one of primary concern and magnitude.

More research is needed to improve existing therapies and development of new treatment modalities. While existing drugs relieve some suffering they do not work in all cases. In some patients irreversible side effects (particularly tardive dyskinisia) develop. We are encouraging responsible research in these vital areas in the Department of Mental Health in Massachusetts. We have developed clear guidelines which promote needed research while protecting the legal and human rights of subjects.

It is our hope that current and future research will make further dramatic improvements in patient care and prognosis. More people will be able to leave institutions and return to their communities and homes. Research funds must be allocated for developing community residential care with proper supervision. Ultimately improved treatment modalities which minimize side effects together with non-residential care will greatly reduce our annual expenditures for mental illness.

The mentally disabled, who will ultimately benefit from further essential research, are often not in a position to exercise their best judgment or to fully safeguard their rights. Thus, it is essential that as research is planned, there must be strict review standards and procedures designed to protect the legal and human rights of all

patients participating in this research. Special care must be taken in the areas of consent, the method of obtaining consent and the opportunity to withdraw from a research project. The standards must be especially clear in research where there is more than minimal risk to the patients, or where new drugs are involved. In Massachusetts, we have just developed a set of comprehensive guidelines for research in the vital area of mental health. We attach a copy of the summary of these regulations for your consideration in the federal guidelines.

I will be eager to attend the conference on principles of research in health in Washington on October 3 and 4.

Sincerely,

Myra Gordon
Legal Counsel

Research Monitor

MG:jmm Enc.

DEPARTMENT OF HEALTH SERVICES

2151 BERKELEY WAY BERKELEY, CA 94704 (415) 843-7900, Ext. 246



July 28, 1978

Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

This letter is in response to your recent memorandum regarding <u>HEW Multi-Year</u> Strategy for Support for Health Research.

One major concern I have is the present lack of an adequate system to support important public health research in this country. New or previously unrecognized problems (e.g., Legionnaires' Disease, Infant Botulism, Guillain-Barré Syndrome, etc.) appear unexpectedly. Yet, when they are recognized, there is no national mechanism for rapid and intensive study of such problems.

Of the new, or previously unrecognized problems listed above which "surfaced" in 1976, only Legionnaires' Disease has been studied intensively at the federal level. The Center for Disease Control's (CDC) study of Legionnaires' Disease was stimulated to a great extent by the extensive public and political attention directed to this disease problem.

No such national effort has been devoted to necessary epidemiologic and laboratory studies of Guillain-Barré Syndrome and Infant Botulism. Recent studies, which have not been supported by the U. S. Public Health Service, have shown that infant botulism causes some cases of sudden infant deaths. A recent report from England confirms that this newly recognized infectious disease process is of international scope. It is thus incredible to me that almost two years from its initial recognition as a serious infectious disease of infants, no substantive efforts have been made at the national level to study this problem.

At the present time, the U. S. Public Health Service does not have a system which is able to respond in timely fashion to support research on emerging public health problems. The NIH grant application process is too slow and CDC has no funds to support extramural research.

In the development of a multi-year strategy for support for health research, a responsive system for support of research on new or previously unrecognized public health problems is sorely needed.

Sincerely,

James Chin, M.D., Chief Infectious Disease Section

- James Chin

and

President, Conference of State and Territorial Epidemiologists

3-152



SCHOOL OF NURSING

(414) 963-4801

September 5, 1978

Dr. Donald S. Frederickson
Director, National Institutes of Health
Department of Health, Education, and Welfare
Building 1, Room 124
9000 Rockville Pike
Bethesda, Maryland 20014

Dear Dr. Frederickson:

I am writing on behalf of a conference group of nurse researchers who are either Principal Investigators or Project Directors of HEW funded research grants. The majority of the members of this Association are responsible for performance on institutional grants intended to facilitate research in nursing. As you know, this important effort is seriously threatened because of the cut-off of funds to the Division of Nursing.

The chief purpose of this letter, however, is to convey to you our comments on the first draft of Health Research Planning Principles. We offer these comments/suggestions in the hope that you will give them serious consideration in the process of developing the set of principles NIH ultimately adopts. Specifically, we are concerned with four issues: 1) that more of the federal research dollar be allocated to institutional support for research in nursing; 2) that nurse scientists/researchers have adequate representation in the group of researchers who critique the first (and subsequent) draft of the Planning Principles; 3) that the substantial role of nurses in the testing and application of research findings in delivery of health be explicitly acknowledged and 4) that this role be supported in the operational application of any national (NIH) plan for the support of health research.

Reference

Comment

- Principle #1 Nursing research is vital to the improvement of providing
 "the highest quality health care". The majority of current
 research in nursing is at the applied level: e.g. developing
 understanding of how persons can live better with chronic
 disabilities; teaching and assisting people to maintain
 wellness; identifying and treating health problems to
 prevent their becoming illness problems.
- Principle #2 Encouraging interdisciplinary research would be one tangible way of identifying future alternatives. At present the research funding process encourages disciplines to confine research to discrete areas of specialization. This discourages synthesis of knowledge and the discovery of directions for future research -- and possible applications to health care.

Dr. Donald Frederickson September 5, 1978 Page 2

Reference

Comment

Principle #3 Present research capabilities are neither widely enough supported or <u>sustained</u>. Specifically, federal support to nursing is extremely limited with respect to the large contribution nursing research makes to health.

The Report of the Committee on a Study of National Needs for Biomedical and Behavioral Research (1977) of the National Academy of Sciences explicitly recommends increased support to prepare nurse researchers and enlarge the research effort in nursing. (Please see the National Research Council Report, pp. 160-163.)

- Principle #4
- (a) There should be a stronger base of <u>institutional</u> support for research. Nursing in University settings should be given specific consideration in this regard. Many university schools of nursing are conducting significant research at the <u>same time federal support for institutional research</u> is <u>decreasing</u>. They also "team" with settings where care is delivered.

Significant reduction in morbidity for high risk mothers and infants is one important outcome of such researcher - practitioner collaboration.

- (b) Prevention and health maintenance are the specific provinces of nursing. Nurses form the largest single professional cadre managing these aspects of health.
- (c) Opportunities for young investigators. Some of the most creative and potentially fruitful ideas come from young investigators. We believe "seed" money should be available for these young investigators.

I trust these comments will prove useful to you in both staff and peer deliberations regarding the forthcoming Planning Principles. If you wish additional information, I shall be glad to provide it, or, identify an expert who can provide it.

Thank you for your consideration.

Sincerely,

Mary E. Conway, Ph.D., FAAN

Dean and Professor

Principal Investigator, DHEW Research Grant 1R02NU00648

MEC:dq

cc: Dr. Henry Foley

Health Resources Administration

Hyattsville, Maryland

Dr. Doris Bloch

Department of Health, Education & Welfare

Nursing Research Branch - Division of Nursing

Hyattsville, Maryland

B-154

OFFICE OF THE PRESIDENT

August 7, 1978

Mr. Joseph A. Califano, Jr.
Secretary of Health, Education and Welfare
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Room 615F
Washington, D.C. 20201

Dear Mr. Califano,

We've read with great interest of your plan to design, develop and implement a five year health research plan to put into perspective and organize the work being supported by NIH funding. We want you to know that the general consensus of the Foundation's leadership is supportive and that we look forward to participating in the health conference scheduled for October.

I've been away and have not had the opportunity to respond to your call for suggestions and thoughts. I hope therefore that this short note is not late enough to have become superfluous. Might I ask you to seriously consider the millions and millions of dollars raised by national voluntary health agencies in the name of basic and clinical research and to make some effort to place those funds in the overall perspective of a five year research plan.

Now it might appear to you that I am suggesting that the Board of Directors of these national agencies would be willing to abdicate the power and responsibility of dealing with these, but that is not my point. The fact is that as the NIH commitment has grown in the past two decades, the role of the voluntary agency's research programs have changed dramatically. In most cases, perhaps too many cases, those millions are now disbursed to a "formula" established by an agency's National Medical Advisory Board, one no more than a carbon copy of the peer review system operative in the institutes at NIH. Available research monies therefore become either a supplement of grants already offered to successful NIH grantees, a substitute for NIH monies when the grant falls slightly below a cut-off point or offered to an investigator who didn't or wouldn't go through the bureaucratic grant procedures established by NIH. Where once volunteer agency research money went into genuine areas of interesting research - research that would be considered too risky or "far out" for those in the peer review system, that is no longer the case. The best that can be said about these research monies is that they have helped to fund fellows - especially in these difficult days when NIH has been forced to seriously curtail fellowship monies.

(continued)

COOLEY'S ANEMIA FOUNDATION, INC.

Joseph A. Califano, Jr. August 7, 1978 Page 2

Additional truths: lay members of these National Boards of Directors are almost always influenced in a most primary way by the physician/scientists recruited to the organization - and to some great extent that should be true. But too often the lay section of these Boards is reluctant to question and therefore challenge directions taken by the expert physicians - and valuable research monies, raised with much difficulty, are gone.

We hope that your staff will find it possible to seriously examine the possibility of direct input of these monies into some overall plan. I expect that you will find major support from those lay directors of mational organizations who feel that more could be done with the millions distributed by private voluntary agencies. I promise the involvement of my staff in this effort.

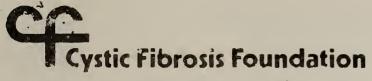
We look forward with interest and support to your efforts in this area.

Most cordially,

William J. Celentano

President

WJC: ar



Public Policy Office:

6000 Executive Blvd , Suite 508, Rockville, MD. 20852 • (301) 881-2774

August 2, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health Educationa and Welfare Hubert H. Humphrey Building Room 615F 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Mr. Secretary:

We appreciate your courtesy in furnishing us with a copy of the information on the health research planning efforts now in progress in your department. As the representative of thousands of children and young adults whose only hope for life lies in health research. We are committed to maintaining the strengths of the research community.

The Cystic Fibrosis Foundation strongly supports the concept of planning. As you know, our recent report, "Cystic Fibrosis: A Plea for a Future," which accompanied the NIH report on cystic fibrosis, was prepared in an effort to rationalize, coordinate and plan programs to deal with this major health problem. In addition, we are now preparing five-year strategic and operational plans for our Foundation.

The NIH "Draft Statement" of planning principles contains praiseworthy objectives that few would argue with. What was missing, and what I trust will emerge from later developments, was an explanation of how those guidelines will be translated into a plan, how that plan will be updated from year to year, and how that plan will affect the actual decisions made in your Institute and across HEW.

I hope the plan will never become so rigid or binding as to take away the opportunity for other considerations to help shape research directions. I believe that one of the principal reasons health research has fared so much better than other kinds of federallysupported research in the last decade is that Congress feels much more involved and welcome in the health field than elsewhere. Without diluting the quality of the research in any way, NIH has remained responsive to Congressional mandates, and the resulthas been continued growth. This relationship should be and deted.

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GABRIEL KAPLAH

National Chairman

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Secretary Joseph Califano August 2, 1978 Page 2

As the plan develops, I hope the Department will keep in mind the importance of biomedical and behavioral research as an independent mission of the Department, supporting the entire medical sector of our society (and the world). It can never exist simply to promote the other HEW missions of direct federal health care delivery, cost control regulation, and the like. The point is obvious, yet it is possible to read your speech of April 29 (particularly the fifth principle on page 13) as saying the opposite.

Further, I hope that any set of priorities for research that is based upon measures of disease incidence and mortality will not be simplistic, but will instead include a number of factors. For example, a disease which attacks and kills children should be afforded a higher priority than a disease which kills the same number of senior citizens (if such a choice has to be made), because society can benefit from years of productive life from the people who survive childhood diseases. Similarly, the severity of a disease, the length of time it affects a person (and at what monetary and personal cost) before death, the number of bodily systems it attacks, its similarity to other diseases which could benefit from successful research, and other concerns should all be taken into account. The temptation must be resisted to simply apply "dollars per patient" or "dollars per death" tests in allocating research spending. This has never been done in the past, and I hope it does not happen as a result of the planning process.

The Cystic Fibrosis Foundation would be pleased to assist you in any way we can in the planning process. Do not hesitate to call on us.

Sincerely,

Doris F. Tulcin President

UNIVERSITY OF MARYLAND HOSPITAL

REDWOOD AND GREENE STS. BALTIMORE. MARYLAND 21201

CLINICAL LABORATORIES

August 15, 1978

Joseph A. Califano, Jr., Secretary Dept. of Health, Education & Welfare Washington, D. C. 20201

Dear Mr. Califano:

I am delighted that you addressed the Amer. Fed. for Clin. Research at its annual meeting in San Francisco in April. I regret that I could not be there at the first AFCR meeting I have missed in over 10 years. Why? Because all previous meetings were conveniently held on the East Coast and our increasingly complicated schedules would seem to require some consistency in our year to year expectations and obligations. Of the half dozen or so national clinical research meetings I attend each year, the AFCR annual meeting has been the only one of general medical interest. It is thus been the most important inter-disciplinary medical research meeting in spite of not being the most relevant one for my particular field. However, it has given me the inter-disciplinary stimulation and exposure which you expressed in your third tentative principle.

Importantly, I began my response to your memo of July 19th while reading your 4th principle which expressed concern over how we spend less than $1\frac{1}{2}\%$ of our health care and research dollars on health research. That small figure which I calculated from the figures in your April talk is alarming and I think you will agree that it is equally as disturbing. Previous speakers at the annual AFCR meeting have talked of the disproportionate low amounts spent on research in health care compared to technology in science and industry. Some have talked of the high cost of dialysis, coronary artery surgery, reflecting on the relatively small cost of the development of polio vaccine and Rh immune globulin. No doubt the problems are different but the impact of a success in medical research, if it is a translatable success, always seems to be truly extraordinary. You seem to imply, and even question whether the billions, (\$180 billion in Fy 1979) spent on health care had any impact whatsoever on the health of the American people. You remind me of something I have expressed dozens of times as to why I am doing research and no clinical practice: "Medical practice is analogous to putting ones fingers in holes in dikes and medical research represents an opportunity to build a better dam".

You follow your health cost care statement and questioned its effect on the health of the American people with the implied, even stated, notion that breakthroughs in research not only improve health but lower the costs associated with disease. Next you asked us to relate to our Schools of Public Health. We do not understand them,

as basic researchers. We hardly know what they do except that, in general they survey health problems -- with fancy statistics -- about which we already have implicit knowledge. However, your point is indeed well taken. You have highlighted some of the major problems in health. But it has seemed clear to me all along, and you seem to clearly express the position that basic science "discoveries" will greatly decrease the cost of health care.

The government liason staff member of my national association, the American Association of Blood Banks, suggested that your last two tentative principles caused a furror at the spring meeting of the NHLBI. I think they are on target. Further, I look forward to your October conference at the NIH. Please send me a copy of your proposed principles if they differ from those expressed at the AFCR meeting in April.

I apologize for not providing more thoughtful input for you, but I first saw your address this month after returning from an international hematology and blood transfusion meeting in Paris. We do need five year or three year plans or some way other than the current, frantic yearly rewriting of an application. For your interest, you should be aware that the highly productive researcher spends much more of his "productive time" preparing his yearly grant applications -- as opposed to the less productive one or two paper per year researcher. As a 10-15 paper per year researcher, I will turn out that many papers per year as part of my annual report to my granting agency. It is distressing, that I spend as much time on my grant renewal application as on the papers. In contrast, the one or two paper per year researcher spends as much time writing those papers as he does in preparing his annual grant renewal. Thus, the most productive researchers would seem to be penalized by the requirements for frequent renewals because of the very reason that they are granted; that is, their productivity. Of course, I realize that there are 3-5 year grants awarded by the NIH. But, alas, there are many 1 year reapplications required at NIH and the practice is similar in some of the other federal granting agencies such as the Dept. of Defense. If you are successful only in refining the process of grant applications and thus the efficiency and productivity of the researchers that you and President Carter are concerned with, you will perform a useful service. However, it seems that you will do much more than that. Your June issue of Time Magazine is appropriate for the respect you hold and for your stature as well as, of course, for the desperately needed publicity and enhanced awareness that your Department deserves. Your concern for the Department and the high priority given by Mr. Carter to these programs, deserves at least as much in public awareness as Mr. Johnson received for his "Great Society" program. Please let me know if I can help you in any way.

Yours very truly,

R. Ben Dawson, M.D., Director Blood Bank Transfusion Service Professor, Dept. of Pathology Associate Professor, Dept. of Medicine

Director, Blood Research Lab



THE WORCESTER FOUNDATION FOR EXPERIMENTAL BIOLOGY

Threwsbury, Massachusetts 01545

Telephone (617) 842-8921

August 23, 1978

Dr. Donald S. Fredrickson
Director
Department of Health, Education,
and Welfare
National Institutes of Health
Bethesda, Maryland 20014

Dear Dr. Fredrickson:

I am responding, on behalf of the Delegation for Basic Biomedical Research, to Secretary Califano's request for comments in developing a multi-year strategy for health research. We view this effort most worthy and timely. We want to express our appreciation for having been invited (according to letter from Kurt Habel July 26, 1978) to submit our views.

The remarks that follow are a condensation of comments made by members of the Delegation to various Congressional groups and committees and to Dr. Press and his staff during the past nine months as they too have urged consideration of a national health research plan.

It is abundantly clear to medical scientists and a significant segment of the public that substantial further improvement in the health of the American people, with attendant cost reductions, awaits the acquisition of much more basic biological knowledge about normal and abnormal cell and body function. The major killers and disablers like cardiovascular disease and mental illness, cancer, and arthritis are now the enemies, as once were other equally fearsome ills. But they can be controlled and defeated by the methods of basic research.

Our optimism and confidence in the effectiveness of basic research is rooted in the history of its accomplishments. Consider: the virtual elimination of lobar pneumonia, polio, tuberculosis, plague, cholera, smallpox, diphtheria, measles, syphilis; the subduing of yellow fever and malaria; the impact of vitamins and other nutritional factors on human health, including the lengthening of life expectancy by 30 years during the last century; the availability of Xrays for diagnosis and treatment; the ability of women to control their childbearing; organ transplantation and cardiovascular surgery; the successful treatment of Rh disease of the newborn; improvements in treatment of hormonal abnormalities; and the chemical control of mental illness. These remarkable triumphs are the result of basic research—the application of human curiosity, imagination and experimental ingenuity to nature's mysteries.

Basic research produces the library of knowledge from which applied research borrows to bring help to the suffering.

There is no question that the diseases we now confront present more formidable problems to the scientist than those already vanquished. But it must be remembered that during the last 40 years our knowledge base has grown at an astonishingly rapid pace, presaging early application to the more intractable problems of human disease. Government-supported research in: the structure and function of cellular membranes; the cellular control of gene expression; chemical and viral carcinogenesis; mode of hormone action; immunology; genetics; and neurobiology now hold particular promise for the eventual prevention, cure or control of cancer, cardiovascular disease, genetic disease, arthritis, endocrine disorders, allergic and autoimmune disease, and mental illness.

In spite of the overwhelming evidence of the effectiveness of basic science in eliminating and controlling human ills, we as a nation are spending a paltry one-half of 1% (about \$1 billion) of our health care expenditure (about \$200 billion) on basic research. While the budget of NIH has risen over the last decade, the real dollar support for basic research has failed to keep pace with the nation's potential for doing that research. Our limited resources are increasingly directed toward applied "research" aimed at limited objectives to alleviate immediate problems.

The U.S. Government has created and generously implemented the most effective device known to man for initiating and nurturing the best in research: the scientist-initiated, peer-reviewed project grant. But we have, in recent years, lost sight of this unique contribution in favor of program-project grants, center grants and contracts, support vehicles better suited to bureaucrats than to scientists.

Continued development of technology based on inadequate knowledge is short-sighted, wasteful and extremely expensive.

The nations's community of basic biomedical researchers is discouraged, demoralized, without adequate funds either to conduct research or to train young scientists to man the laboratories of the future.

Criticisms that basic science is not relevant to the needs of people arise from a profound misunderstanding of the process. No matter how much we might wish it to be otherwise, the laws of nature that give us the power to control disease have applicability only after they have been discovered. The unknown yields up its secrets in ways we can't forecast. We only cripple our efforts if we insist that scientists only explore nature in the name of particular diseases: cancer, heart, arthritis. Basic research is relevant to the needs of society by definition, because it works: it produces knowledge which gives us power to maintain health and subdue disease.

Mahlon B. Hoagland, before the House Labor, HEW Subcommittee on Appropriations, April 18, 1978

In the past ten years there have been two major factors which have eroded the vigor and effectiveness of American biomedical research:

- 1) Lack of total funds to cope with three kinds of inflations, each 10% or more annually:
 - a) Cost of living and doing things
 - b) Increased sophistication of biomedical technology
 - c) Increased pool of highly trained researchers and desirable projects.

For lack of annual increments to meet these increased needs, the level of the research enterprise has been diminished.

2) Preference for applied research with immediate relevance and promise of quick payoffs over long-term basic studies with little promise for early solution of a disease problem.

Comment of Dr. Arthur Kornberg in letter to Senator Edward Kennedy March 27, 1978

- 1. There has been no increase during the last decade in NIH constant dollars or real dollars for new research grants (ROls). The FY1979 budget anticipates a substantial drop in such funds.
- 2. Most NIH institutes maintain a 60% budget commitment to ROls, a proportion deemed by the members of the Delegation to be reasonable. The notable exception is NCI which commits only 21% to ROls. Owing to NCI's large budget, its low emphasis on project grants reduces NIH's overall emphasis to 41%. Correcting the NCI figure for basic research supported by centers and POls, we obtain an estimate of 35% for basic research. This still sharply reduces NIH's overall commitment to basic research.
- 3. Owing to an over two-fold increase in the number of applications submitted to NIH in the 1970s, the award rate has recently run at about 40%. It is expected to drop to below 30% in FY1979.
- 4. Goals for NIH program emphasis in the coming years should be: 18% for intramural and program management; 60% for ROls; 12% for centers and POls; 6% for contracts and 3% for BRS grants.

Delegation letter to Senator Edward Kennedy, March 22, 1978

The U.S. Government has created and generously implemented the most effective device known to man for initiating and nurturing the best in research: the scientist-initiated, peer-reviewed project grant. But we have, in recent years, lost sight of this unique contribution in favor of program-project grants, center grants and contracts, support vehicles better suited to bureaucrats than to scientists.

Continued development of technology based on inadequate knowledge is short-sighted, wasteful and extremely expensive.

The nations's community of basic biomedical researchers is discouraged, demoralized, without adequate funds either to conduct research or to train young scientists to man the laboratories of the future.

Criticisms that basic science is not relevant to the needs of people arise from a profound misunderstanding of the process. No matter how much we might wish it to be otherwise, the laws of nature that give us the power to control disease have applicability only after they have been discovered. The unknown yields up its secrets in ways we can't forecast. We only cripple our efforts if we insist that scientists only explore nature in the name of particular diseases: cancer, heart, arthritis. Basic research is relevant to the needs of society by definition, because it works: it produces knowledge which gives us power to maintain health and subdue disease.

Mahlon B. Hoagland, before the House Labor, HEW Subcommittee on Appropriations, April 18, 1978

In the past ten years there have been two major factors which have eroded the vigor and effectiveness of American biomedical research:

- 1) Lack of total funds to cope with three kinds of inflations, each 10% or more annually:
 - a) Cost of living and doing things
 - b) Increased sophistication of biomedical technology
 - c) Increased pool of highly trained researchers and desirable projects.

For lack of annual increments to meet these increased needs, the level of the research enterprise has been diminished.

2) Preference for applied research with immediate relevance and promise of quick payoffs over long-term basic studies with little promise for early solution of a disease problem.

Comment of Dr. Arthur Kornberg in letter to Senator Edward Kennedy March 27, 1978

- 1. There has been no increase during the last decade in NIH constant dollars or real dollars for new research grants (ROls). The FY1979 budget anticipates a substantial drop in such funds.
- 2. Most NIH institutes maintain a 60% budget commitment to ROls, a proportion deemed by the members of the Delegation to be reasonable. The notable exception is NCI which commits only 21% to ROls. Owing to NCI's large budget, its low emphasis on project grants reduces NIH's overall emphasis to 41%. Correcting the NCI figure for basic research supported by centers and POls, we obtain an estimate of 35% for basic research. This still sharply reduces NIH's overall commitment to basic research.
- 3. Owing to an over two-fold increase in the number of applications submitted to NIH in the 1970s, the award rate has recently run at about 40%. It is expected to drop to below 30% in FY1979.
- 4. Goals for NIH program emphasis in the coming years should be: 18% for intramural and program management; 60% for ROls; 12% for centers and POls; 6% for contracts and 3% for BRS grants.

Delegation letter to Senator Edward Kennedy, March 22, 1978

VIEWS ON ADAMHA

As opposed to the NIH, ADAMHA did not establish a Division of Research Grants and study sections representing the pertinent disciplines and problem areas under that Division. Instead, it designated what the director considered to be the important problem areas ten years ago, and established an administrative branch, budget, and one or more study sections for each. In that organization fundamental research, research in the various biological disciplines pertinent to mental illness, drug addiction and alcoholism, were represented not at all or inadequately, and important areas of mental illness and intellectual disorder such as schizophrenia, affective disorder, senile psychosis and mental retardation, were all lumped together under a single Clinical Research Branch. organization which has not changed for ten years, consolidated the polarized attitudes and priorities of a decade ago and did not provide the flexibility to respond to increasing knowledge and new opportunities.

There is thus a need for a reappraisal and reorganization of ADAMHA, establishing an internal structure similar to that which has been found to be effective in the various institutes of NIH, the establishment of a Division of Research Grants and appropriate changes in the study section structure that would make it more representative of the range of basic disciplines that are pertinent and an appreciation of the problems as they are seen today. The new Administrator of ADAMHA has apparently recognized these needs and has recommended a reorganization of the Administration and its study sections. We would urge your support of his recommendations.

Dr. Seymour Kety, letter to Senator Edward Kennedy, March 20, 1978

OTHER RECOMMENDATIONS

- 1. Of fundamental importance to the health of the research enterprise is a vigorous <u>peer-review system</u>. There is an urgent need to reduce the burden on peer-reviewers by increasing the number of reviewing groups and reducing the length of applications. More focus is needed on the quality of the <u>applicant</u>, not the application.
- 2. The selection of institute Council members needs to be more rigorously attentive to the need for competence. There

should be substantially more input from the scientific community than now exists.

- 3. The Director of NIH should be given more <u>control</u> over fund distribution among the institutes.
- 4. Support for science must be more <u>stable</u>. This objective would be aided by:
 - a) Careful attention to the affect of each year's appropriation on the following years commitment base.
 - b) Longer grant periods.
 - c) A five year plan.
- 5. There is a great need to find ways to reduce the red tape scientists and research institutions need to contend with when receiving government support. An excellent study of this report has been made recently: Smith and Karlesky, "The State of Academic Science" Vols. I and II. Change Magazine Press, NBW Tower, New Rochelle, N.Y. 10801. See particular Vol. II pg. 184-187.
- A five year health research policy is sorely needed, particularly to insure a renewed and vigorous commitment to exploration, discovery and venture research -- basic research. It is too easy in the day-to-day budgetary hassles and competition for limited funds, to take the short-sighted and more glamorous route of supporting clinical programs, centers, big contract programs having a disease-oriented short range bias. But if we are to make real progress in understanding disease we must be prepared to support individual creative effort by young scientists, over a long time span - i.e. let science operate as history has shown it must operate. There is no substitute for the brilliantly conceived support device we now have - the investigator initiated project grant. Other bureaucratic support mechanisms such as centers, program-project grants, contracts serve the quest for knowledge poorly and should be reduced in amount and limited to applied and developmental areas.

Sincerely,

Milaklar -13. Hragland

Mahlon B. Hoagland, M.D. Scientific Director



UNIVERSITY OF SAN FRANCISCO

August 17, 1978

The Honorable Joseph A. Califano Secretary of Health, Education and Welfare Humphrey Building 200 Independence Avenue NW Washington, DC 20201

Dear Mr. Secretary:

Thank you for inviting my comments on your "HEW - Multi-Year Strategy for Support for Health Research" presentation. May I say that you are to be congratulated for initiating increased government support for biomedical research. As you point out in your presentation, basic research in this area has not only furthered our knowledge of the human body and of organisms in general, it has also led to important and sometimes "miracle" cures of previously rebarbative illnesses.

One thing I missed in reading your stimulating presentation, Mr. Secretary, is a proposal for an ethical framework within which to view the proposed biomedical research. On page six you express regret over the lack of "...an across-the-board strategy for health research that assesses research and health needs in a systematic and comprehensive way." Surely, the overview most urgently needed is an ethical one. For when "...we ask whether our health research effort bears a reasonable relationship to the basic burden of illness in America -- including mortality, disability, and cost," we are seeking judgments about the priorities of human life. This quest leads us inevitably into the arena of ethical life.

Consider, for example, the matter of cost. The decision of how much money to spend on the care of the sick, especially the aged and indigent, presupposes judgments about the value of human life itself, about the imperatives of justice regarding society's duties toward the needy, and about the priority such medical care and the research upon which it rests shall enjoy in relation to other government projects. One thinks here of Dr. Walter Sackett's proposal that the state of Florida legalize the withholding of medical treatment from the seriously retarded inmates of that state's mental institutions -- treatment that promises to cure the patient -- allowing them to die, say from pneumonia, thereby saving the state millions of dollars. Here we have an ethical judgment to the effect that, in some cases at least, economic considerations shall enjoy primacy over human life because the latter is broken and therefore costly to maintain. What are the ethical considerations involved? Can such a policy be reconcilled with the ethos of democratic society?

And surely an ethical framework is demanded when biomedical research and health programs cover such sensitive issues as we find enumerated on page ten: "...the aging of the population, or new methods of fetal research...and universally acceptable methods of family planning, (and to) explore methods of producing healthy

B-169 CAMPION HALL SAN FRANCISCO, CALIFORNIA 94117 415/666-6355 babies by correcting fetal deficiencies..."

It is by now clear that an anti-age cult is emerging which seeks growing support for the legalization of euthanasia, both voluntary and involuntary, for the aged and the infirm. As the birth rate continues to decline and the aged population continues to grow, pressure will mount for euthanasia as a shrinking working population groans under the weight of heavier and heavier taxes for Social Security and Medi-Care payments.

What is HEW's position on research on previable fetuses that have survived abortion? Experimentation on human beings -- even on those destined to die within a few hours because aborted -- signals acceptance of the theory that human beings may be used as mere means to an end, as objects of social and scientific purpose. This theory is fatal to democracy.

The prospect of insuring healthy babies by correcting fetal deficiencies is uplifting, but it also confronts us with eugenic practices. Will such correction involve marriage and birth selection by the government, coerced sterilization, infanticide and abortion? One cannot avoid recalling the 3400 Navaho women who were sterilized two years ago by HEW or the two retarded black sisters who were sterilized without their consent or their parents' consent, again by HEW.

All the above points represent cases of biomedical activity which rest upon philosophical and theological judgments about the nature, dignity, and rights of the human person. The kind of biomedical research encouraged and underwritten by HEW will have enormous influence on the future of democracy just because that research touches the human person in these crucial areas. Should these judgments be left in the hands of scientists and physicians to be second-guessed by government officials and elected representatives? In my judgment this would be a serious mistake. It would in effect say that scientists and physicians are the most competent in the area of biomedical research and policy. Obviously they are on the level of biomedical research. But since such research and its policies involve ethical judgments, it is clear that on the more fundamental level -- the level of the implied philosophical and theological judgments about human nature and the goals of democracy and civilization, on what constitutes human progress, etc., they are not the most competent. It is necessary to have the benefit of those who are by education and profession dedicated to the investigation of such matters.

I respectfully recommend, therefore, Mr. Secretary, that, in line with your expressed intention (page seven) to seek the advice and counsel from all quarters for the development of a five-year research strategy, you include philosophers, theologians, and political scientists among the first group of advisers and counselors. This would permit a healthy, balanced, and constructive interaction in your conferences, an interaction which will protect and promote the values of democratic society.

Again, thank you for inviting my comments. I hope they will be useful. If I can be of any further assistance, please do not hesitate to inform me. I have enclosed a copy of one of my articles, "The Philosophy of Human Experimentation," which discusses more fully the points advanced in this letter.

Sincerely,

B-17

Raymond Dennehy, Ph.D.

cc: (Mrs.) Judie Brown, Nat'l Right to Life Enclosure: article, "Philos. of Human Exper."

Campion Hall

Down's Syndrome Congress
Cooperating with NARC

LEGAL ADDRESS: 529 S. KENILWORTH, OAK PARK, ILLINOUS ANTOIN

A NATIONAL ORGANIZATION OF PARENTS AND PROFESSIONALS CONCERNED WITH DOWN'S SYNDROME

Reply to:

30 July 1978

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EDITORS Down's Syndrome News

DIANE CRUTCHER Normal, Illinois PENNY SCHIMPLER The Honorable the Secretary of Health, Education, and Welfare Joseph A. Califano, Jr. Department of Health, Education, and Welfare Washington, D.C. 20201

Dear Sir:

Your memorandum to professional societies and health organizations, subject: HEW Multi-year Strategy for Support to Health Research, dated 19 July 1978 was well received. I have written my thoughts to Dr. Donald Fredrickson whom you designated as the man to direct the effort in planning the National Conference on October 3-4, 1978.

Dr. Fredrickson has been sent a copy of the Down's Syndrome Congress' House and Senate testimony regarding NIH budgets, with emphasis on basic research. Further, I have informed him of the Down's Syndrome Congress independent professional survey which will soon establish our suggested priorities of research. Input from the survey has been provided from many professional medically oriented and consumer people. We hope to have our survey results in time for the NICHHD 17-19 September, Boston, MA, International Symposium on Down's Syndrome Research.

Thank you for the opportunity to contribute. Our organization consists mostly of consumers which can provide an important dimension to worthwhile endeavors such as you have set out to achieve in the form of a multi-year strategy on allocation of health research dollars.

I have extracted portions of your 29 April 1978 remarks to the American Federation for Clinical Research. My intent is to pass along your basic ideas to the Down's Syndrome Congress constituency thru our monthly Down's Syndrome News newspaper.

Respectfully,

President

Down's Syndrome. Congress

B-171

Dr. Donald F. Fredrickson Director. National Institutes of Health Bldg 1, Rm 124 Bethesda, MD 20014

Dear Dr. Fredrickson:

By way of introduction I am the President of the Down's Syndrome Congress. This letter to you is in response to an opportunity afforded me by Secretary Califano. His 19 July 1978 memorandum, subject: "New Multi-Year Strategy for Support for Health Research" sent to the Down's Syndrome Congress suggested we write you. Accordingly, the following is submitted for your consideration:

- a. Over the past two years the Down's Syndrome Congress has corresponded with your NICHHD in an effort to obtain information, which has been graciously provided and to encourage increased research into causes and prevention of Down's Syndrome which is yet to materialize. We have also dealt with the Congress of the United States and the Secretary of HEW on the same subject. We feel more basic research and training should be accomplished regarding causes, prevention and education of Down's citizens. We also feel a coordinated effort regarding current research, future research and collection and dissemination of accurate data regarding Down's Syndrome is needed. A longitudinal effort:
- b. Enclosed is our April 1978 testimony submitted to all members of the House and Senate Appropriations Committee.
- c. We the Down's Syndrome Congress have a survey underway which, when completed, we intend to present to you for consideration. Professpr John Rynders of the University of Minnesota and a member of our Board of Directors has gathered input from professional medical, educational, consumer personnel concerned with Down's Syndrome. This survey is now being refined so we can identify areas of necessary research, and a consensus order of priority where possible. Our target date for completion is prior to the 17-19 September 1978 International Symposium on Down's Syndrome Research to be held in Boston, Mass.

The 17-19 September 1978 International Symposium and your Multi-Year Strategy 3-4 October 1978 Conference are encouraging signs. We the Down's Syndrome Congress attach great importance to your efforts and have high hopes and great expectation that more importance, effort, money and priority will be granted research and attention to Down's Syndrome within all your Institutes.

The Down's Syndrome Congress is pleased to be heard and wants to be kept informed.

Thank you for your consideration.

Respectfully,

ROBERT E. GLASGOW, MA President Down's Syndrome Congress

Cy furn: Executive Committee Professor John Rynders



Suite 406 • 1828 L Street, NW • Washington, D C 20036 • (202) 293-2930

August 8, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

Thank you for this opportunity for the Epilepsy Foundation of America to contribute to the Department of Health, Education and Welfare multi-year strategy for support of health research.

As you know, the National Commission for the Control of Epilepsy and Its Consequences carefully studied research needs to develop improved methods for preventing and controling epilepsy. The Commission made seventy-four specific recommendations which, if implemented, would by 1980 achieve a greater understanding of the causes of epilepsy and would develop improved techniques for prevention, diagnosis, treatment and control of epilepsy through research. Copies of these recommendations are enclosed.

We are enclosing also testimony presented to both the House and Senate Labor/Health, Education, and Welfare Appropriations Subcommittees by Dr. Richard Masland, former Executive Director of the Commission for the Control of Epilepsy and Its Consequences, in behalf of the Epilepsy Foundation of America. This testimony addresses the funding need of the National Institute of Neurological and Communicative Disorders and Stroke, the focal point of epilepsy research in this country.

Tpilepsy costs United States citizens more than \$3 billion annually in terms of lost productivity, excess mortality, and institutionalization.

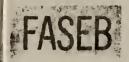
The lementation of these research recommendations is basic to reducing the economic impact of epilepsy to the nation and to returning two million citizens to productive and fulfilling lives.

The Epilepsy Foundation of America is pleased to provide its input to the Desirtment of Health, Education, and Welfare's research strategies and will be happy to meet with you to discuss it further.

Sincerely,

lack McAllister Executive Director

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FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY

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August 7, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Secretary,

This letter is in response to yours of July 19 to Dr. Eugene Hess requesting views and suggestions concerning principles which might inform the development of a five-year plan to guide the allocation of limited government health research dollars among eight agencies of the Public Health Service and the Health Care Financing Administration.

The opportunity to participate in this public planning process is most welcome. Thank you. The scientific community, as a partner of the government in the biomedical research enterprise, believes the joint stewardship of this enterprise should be under continuing review and evaluation, and hopes this particular process will lead to great or and more timely benefits to the public which supports the enterprise. The Federation looks forward to contributing at various points in the process over the next two years, including the National Conference October 3 and 4 in Bethesda. In this connection we would particularly appreciate a copy of the proposed principles before the conference.

Since the Federation is comprised of six learned Societies representing basic biomedical research disciplines, its natural concern and special competence is in the development of new knowledge which forms the science base from which all else proceeds. The home of the science base is, of course, the National Institutes of Health, the first institutional link in the continuum which runs from bench to bedside. We will limit our remarks primarily, if not exclusively, to the science base, leaving it to others more competent to address the problems and opportunities of other institutional links in the continuum.

The Secretary's speech in San Francisco gave repeated heavy emphasis to limitations of government resources and suggested five "tentative principles that might underlie a five-year plan." Briefly stated, they are: 1) We must maintain at a high level and enhance our support for fundamental research into biology and behavior; 2) We must assure that there are ample opportunities for young investigators; 3) Basic research has to be accompanied by vigorous, thoughtful, and where appropriate, interdisciplinary applications; 4) Government-supported research must have a strong orientation toward improving the quality of our nation's health and the effectiveness of the nation's health services; and 5) HEW-supported research must be more effectively oriented to develop knowledge bases that support not just one but all the health missions of the Department -- prevention, delivery, regulation, standard-setting, and cost control.

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In presenting these principles the Secretary characterized them as "neither immutable nor exhaustive." In the context of repeated emphasis on the limitations of government resources, it cannot be predicted how long political or economic factors might permit these mutable or changeable "principles" to operate. Also, it cannot be known how amenable the dynamics of science might be to some of them. But we do know that, whatever statements of goal, practice or policy we elect to treat as "principles," certain immutable natural principles will continue to operate:

One. Our ability to cope with disease varies directly with our understanding of disease. The key to new knowledge is basic research. There is no alternative. There is no other way to get from here to there. What we don't know is hurting us and is costing us.

Two. Scientific discoveries cannot be ordained, requisitioned, purchased or programmed. As the Secretary said elsewhere in his speech, "basic research is nothing less than a long-term investment and we cannot program or order neatly the mysterious and serendipitous ways in which new knowledge is developed." Nature does not arrange her secrets by disease institutes.

Having made these observations, we would like to suggest that the following factors be taken into account in the development of a five-year plan:

- -- Stability of Funding. Nothing in recent years has been more debilitating and destructive of the productivity of the biomedical research enterprise than the chronic undertainties concerning the level and timeliness of support and the continued existence of various programs. Basic research is a long-range, multi-year undertaking requiring prior planning and long-term commitments of individuals and institutions. The added cost of instability is very high in money, time, energy and research effectiveness. The stability and predictability of funding is equal in importance to the level of funding.
- -- Level of Support. How much research can we afford? Perhaps the better question is how much research can we afford not to do? The \$2.7 billion dollars appropriated for the National Institutes of Health in FY 1978 is a staggering amount of money, but it represents only about three per cent of our nation's health expenditures. As the cost of health continues to spiral, that extremely modest percentage devoted to research will continue to dwindle. Is this enough to spend on finding the answers to disease? Is this enough to invest in the development of new knowledge, the ultimate answer to cost containment? In the circumstances, is research really the place to economize? This is not to suggest that biomedical research should go back to a rate of expansion it enjoyed in the fifties and early sixties. Unlimited resources carry no guarantee of research productivity and can bring a different set of ills. Research productivity is more a function of the number of people qualified to do quality research and the number of projects worth doing at a given time. Only the best work should be supported. The way to assure that only the best work is supported is to strengthen the two-tier NIH peer review system and extend its applicability to all mechanisms of research support. At present it is used primarily to determine the scientific and technical merit of investigator-initiated research grant proposals. It is suggested that other mechanisms, such as center grants, program projects, contracts and NIH intramural research programs would benefit from the same kind of review.

- -- Management. It is ironic that the individual given responsibility for development of the five-year plan for all health research components of DHEW is all but powerless to effect substantive change in his own agency. The following quote from the Report of the President's Biomedical Research Panel is particularly instructive: "It is anomalous that the Director, NIH, bears the major responsibility for his agency, yet holds extremely limited statutory authority to achieve agency goals. Consequently, much of what he accomplishes results solely from his personal leadership and the willingness of the Directors of the Bureaus, Institutes, and Divisions of the NIH to cooperate with him. In the case of budget allocation, his role is limited because each Institute Director not only defends the budget of his Institute before the appropriations subcommittees but is fully responsible for allocating it. The Director, NIH, may, with the consent of the appropriations subcommittees of the House and the Senate and those Institute Directors affected, request reprogramming of funds from one Institute to another. This mechanism is timeconsuming and prejudicial to the future budget of the donor Institute and is a poor management tool so cumbersome that it is rarely used." It is difficult to see how the Director, NIH, could implement the Secretary's third principle, calling for interdisciplinary applications, without a large amount of outside help.
- -- Impact of High Emphasis Programs. There is a widely held impression that the high emphasis given to the Cancer and Heart Institutes, which now claim 50 per cent of the NIH budget, has been at the expense of the other Institutes. As Cancer and Heart have been provided increased funds and positions, the other Institutes have had reductions in both. It is felt that this distortion or imbalance in the distribution of resources may work to the detriment of Cancer and Heart on a scientific basis because of the shortfall of support to other programs. This distortion stands to be reflected in recipient institutions which have a responsibility for maintaining a balance of disciplines, education, etc. In contemplating a five-year plan to insure the best return on the research dollar, is this not a worthwhile question to address?
- -- Vitality of the Enterprise. As the Secretary points out in his speech: "The Federal Health Research enterprise has existed for less than a generation." Obviously, the viability and vitality of the enterprise depends on its ability to attract and enlist the brightest young minds in this form of national service. The government has prepared the way for the next generation through the National Research Service Awards program and it must do what it can to make room for youth in assuring that age is not a barrier in competition for grant support.

Again, Mr. Secretary, the opportunity to participate in the development of the five-year plan is greatly appreciated and we shall be looking forward to contributing at other points in the process. The purpose of these preliminary comments is to suggest that in our mind the health of the biomedical research enterprise is not alone a function of the number of dollars appropriated and that regardless of the amount made available there are externally imposed impediments to insuring that the public gets the best return on each of those research dollars.

On behalf of the FASEB Public Affairs Committee, I am

Brian A. Curtis

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BRADLEY R. STRAATSMA, M.D. University of California, L.A.



FIGHT FOR SIGHT, INC.

National Council to Combat Blindness, Inc. 41 West 57th St., New York 10019 PLaza 1-1118

> MILDRED WEISENFELD Executive Director

August 22, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Califano:

I hardly know where to begin in responding to your inquiry asking for the opinions of the voluntary health agencies in formulating future plans. I will try to do the best I can in conveying that I think is vital and important.

The Fight For Sight has been engaged in the effort to enlist public support for research into the many eye disorders resulting in defective sight, partial or total blindness, and I am enclosing literature which will familiarize you with our agency. You will see from this that it was the Fight For Sight which played the leading role of adding "Blindness" to the then National Institute of Neurological Diseases, which was the forerunner to the establishment of the National Eye Institute.

Surely we are aware of the support that has been extended to the field of vision from the Federal government, but I feel strongly that there is not an adequate relationship between NIH and the voluntary health agencies. This has been our experience and it is my suggestion that the Federal government become more familiar with the programs of the voluntary health agencies and cooperate more fully in exchanging information so that the voluntary agencies may be better equipped to augment the assistance extended by the National Institutes of Health.

I also feel strongly that in our field leadership and guidance would be most helpful in an effort to consolidate a number of agencies which have similar programs and that this would eliminate duplication of activities, at times unnecessary "competition" and reduce overhead substantially.

In the field of vision there are, as you are no doubt aware: Research to Prevent Blindness, Inc.; The National Foundation For Retinitis Pigmentosa Research; The Myopia Foundation; Fight For Sight, Inc., and I am sure still other organizations whose names do not come to me at the moment. With leadership on the part of our government I feel that several of these might be consolidated in a common effort that would accomplish far more.

Continued...)

The Honorable Joseph A. Califano, Jr. FIGHT FOR SIGHT, INC.

The Honorable Joseph A. Califano, Jr. August 22, 1978
Page Two

In the field of blindness, that is, those agencies concerned with the rehabilitation and care of the blind, etc., there are literally hundreds of organizations, and again I feel the government can play a vital role in consolidating many of these under an umbrella that could be far more effective than the services now available to visually handicapped individuals.

This, as you will appreciate, takes leadership and objectivity which is often difficult to accomplish on the part of those involved in a specific agency, since each group tends to believe that their program is the most effective. I realize this is not an easy task and I do not know whether you are aware in our field "vision" there has been an effort to accomplish this under the aegis of the various professional groups such as the American Academy of Ophthalmology and Otolaryngology; The Association for Research in Vision and Ophthalmology and others but after a number of years, barely any progress had been made and finally the Committee established for this purpose was no longer actively involved.

I can, of course, only speak for "my field" which I have come to know is most confusing to the public and discouraging to those who support the various organizations. Most important, however, I am convinced more of the funds contributed could be used more constructively for the purpose of the objectives of the various organizations with a reduction in overhead which would result. In addition, duplication would be avoided and a well rounded program in the best interest of preventing blindness developed. Whether or not this is true in other fields, I am not certain, although I would suspect it may well be.

Mr. Califano, as Secretary of the Department of Health, Education, and Welfare, I feel you have an opportunity of making an unprecedented contribution, if at long last the government would take the leadership in bringing together many groups concerned with the same or similar problems and that this would be a tremendous step forward. Again, individuals have tried and have failed in so many instances, but if a representative with the required stature would become involved perhaps the desired objective could be accomplished. To me, as one who has been in the voluntary health field for some 30 years, this is of primary concern and the most constructive suggestion I can offer.

I shall be eager to have your comments and thoughts and if you feel it is indicated that a representative of your Department should meet with me, I am most willing and would make myself available.

Sincerely, Wildred Weisonfeld

Mildred Weisenfeld Founder and Director

MW:ba Encls.

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FIGHT FOR SIGHT, INC.

National Council to Fombat Blindness, Inc. 41 West 57th St., New York 10019 Puzza 1118

> MILDRED WEISENFELD Executive Director

August 31, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, DC 20201

Dear Mr. Califano:

Further to my letter of August 22, 1978, copy of which is enclosed, there is, in my opinion, an important factor which I omitted and one that I feel could be of tremendous assistance in advancing the efforts of the voluntary health agencies.

Mr. Califano, I have found, in my 30 years as Founder and Executive Director of the Fight For Sight, that there is a dearth of trained and qualified individuals to fill positions of executive capacity ... whether it be "know how," in the administration of a voluntary health agency and its many ramifications, the "dos and don'ts" of public relations and fundraising, and particularly persons with the background and ability to oversee and follow through on an awards program such as ours.

It seems that voluntary agencies, such as Cancer, thart, etc., can budget the salary of a medical director, but the agencies with a lesser income cannot absorb this cost and, therefore, the research programs are frequently supervised by the Executive Director, who is, as you know, responsible for many other activities and often does not have the required background to cope with the scientific and technical problems.

It occurred to me that if the NTH and, in our instance, particularly the NET could maintain a file of suitable applicants, and if that is not possible at this time, to undertake the training of such personnel, who would be future candidates, this would be of tremendous assistance in expediting the respective awards programs and thus relieve the Executive Director to concentrate on enlisting more substantial funds.

I feel that there are many interested individuals who would be inclined to pursue such training, but as of now it is nowhere to be obtained, other than by taking a minor position in a voluntary health agency. As you are aware, there are degrees offered in public health, hospital administration and other graduate courses, but nome are geared to meet the needs of the voluntary health agencies specifically.

continued.....

The Hon. Joseph A. Califano, Jr. August 31, 1978
Page Two

I should add that employment agencies are usually baffled and unequipped to refer such applicants and this is a situation which I have had to live with for many years, as I am quite sure many of the other agencies have had to as well. It is for this reason I feel strongly that steps should be taken to recruit and train potential personnel which would be, as mentioned earlier, a very valuable contribution to the voluntary health effort.

Mr. Califano, I would welcome your comments in this regard since I have been in touch with agency after agency over the years and invariably all they have to offer are people who have been trained for social work or hospital administration and the latter will rarely accept a position with an agency such as ours since their field offers far more opportunity and compensation.

The other alternative is to engage people from the commercial field who often do not have the interest, temperment or personality for our type of work and certainly not the training ... this is true in almost every area of our activities.

Again, I shall look forward to your comments and thoughts.

Sincerely,

Mildred Weisenfeld

Eventive Director

MW:js

P.S. One more thought occurs to me ... could your department institute at the various universities a course for this training. I am sure any number of individuals who have worked with voluntary health agencies would be interested, but there is nowhere they can turn for such training. If you will look into this I am sure you will find I am correct in my opinion and recommendation.



FOUNDATION FOR CHIROPRACTIC EDUCATION AND RESEARCH

October 19, 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education and Welfare
Washington, D.C. 20201

Dear Secretary Califano:

It is a pleasure to respond to your memorandum of July 19 regarding DHEW's Multi-Year Strategy for Support for Health Research. We commend you for the Federal commitment to health research consistent with fiscal reality.

As a preface to our response, we believe it important for you to know that the Foundation for Chiropractic Education and Research believes chiropractic to be a discipline of the scientific healing arts concerned with the pathogenesis, diagnostics, therapeutics and prophylaxis of functional disturbances, pathomechanical states, pain syndromes and neurophysiological effects related to the statics and dynamics of the neuromusculoskeletal complex.

Principle I - Fundamental Research

Research procedures for chiropractic should be no different from any other discipline. There are a great deal of empirical data concerning the efficacy of chiropractic; needed is objective evidence of the specific manner in which this treatment is of benefit. The Foundation is confident that no fair-minded thinker doubts the fact that manipulation works. However, meaningful scientific studies must be conducted.

Our major problem still remains the attempted explanation as to the mode of action of manipulation and the scope of its application. For example, except in the case of acute trauma, pain usually indicates tissue threat. It is not merely the stimulation of receptors that mark the beginning of the painful process; that stimulus enters a nervous system which is already a total of its past experiences, traumas, anxieties, cultural factors, etc. These higher processes, past experiences, and the state of the nervous system at the time of stimulus participate in the selection, abstractions and the same series of the information from the total sensory input!

To understand the mode of action of manipulation, we must have a greater appreciation of the combinations of functional reflexes which are disturbed, and which under normal circumstances enables the organism to adapt itself to its internal and external

Secretary Joseph A. Califano, Jr. Washington, D.C. Page Two

environment. While the removal of pain represents the ultimate test of any therapy, the pathophysiological process and its interruption at any given stage is also a method of understanding and establishing its worth.

Much attention has been paid to nerve root compression syndromes at the intervertebral foramina, but we must bear in mind that these are usually the result of prolonged process and represent a small percentage of the subluxations which are manipulated in the every day experience of the average practitioner. These are primarily the conditions which we hope to prevent. We do not know the precise nature of the cause of subluxations or the neurophysiological mechanisms by which they exert their influence.

What we do know is that trauma, whether sudden or slight or as a result of false or poorly judged movements, is a major cause. Prolonged or repeated postural or occupational stresses result in muscle tensions, postural imbalance and contractions of muscles which produce a low grade type of traumatic inflammation and have an effect upon the articular and periarticular structures and functions of the involved areas.

Activity of the muscle itself causes some degree of ischemia and can result in pain, probably through the transfer of "P" substance across the muscle membrane into the tissue fluid, which gains access to pain endings. The pain itself brings about a tonic reflex muscle contraction which intensifies the ischemia, leading to a vicious cycle. These contractions and their effects upon capsules, tendons, fascia, ligaments and joints produce postural asymmetries and limitation of movement and the resultant proprioceptive bombardment may be the initiating factor of anterior horn facilitation.

This in turn leads to the further perpetuation of the muscular contraction by any additional excitation into the same or related neural segments. The resultant stress on the ligamentous capsules and articular surfaces can lead to local inflammation, adhesions and early breakdown of the facet articulations. These articulations and ligaments have a rich nerve supply and local and radiating pain results.

Limitation of mobility decreases the efficiency of the hydraulic system of the vertebral motor unit which is so necessary for the integrity of the intervertebral discs and contributes to its breakdown, hence to the production of hypermotoricity in the same or adjacent segments. Subluxations of the apophyseal joints may follow. We believe that a hypermotoricity, for example of the fifth lumbar could be due to fixation and aberrant movement of the pelvis and/or hip joints. The resultant disturbances of the dynamics of the postural muscles such as the psoas could produce asymmetrical stresses at the lumbosacral articulations. This is a matter for future research.

Secretary Joseph A. Califano, Jr. Washington, D.C. Page Three

The question of how pain is relieved by manipulation still remains unanswered. In the case of myalgia, adhesion and facet subluxation, manipulation could decrease the stimulation of nociceptors by passive stretching to relieve the muscle spasm, by breaking the adhesions and/or mobilizing the fixated facet. This then decreases the nociceptor stimulus.

Drs. R. F. Kibler and P. W. Nathan, "Relief of Pain and Paraestheses of Nerve Block Distal to the Lesion", Journal of Neurological Neurosurgical Psychology, Vol. 23: 91-98, 1960, showed that pain could be abolished in cases of cord and root damage by injecting a local anaesthetic distal to the region of damage. This indicates that the lesion was not the point which generated the pain but impulses from undamaged tissues were necessary to trigger the pain. The questions which then arise are as follows: does the lesion block inhibitory impulses or is there a decrease of inhibitory impulses due to a lack of normal motoricity? Is the manipulation successful because it relieves the nerve root pressure or is the manipulation successful because it increases the nerve root pressure or is the manipulation successful because it increases the nerve root pressure or is the manipulation successful because it increases the nerve root pressure or is the manipulation successful because it increases the amount of inhibitory stimuli by restoring movement to the level that would provide a beneficial proprioceptive bombardment?

There are a number of other research topics impinging upon the efficacy of chiropractic that should be explored. Does the lesion irritate the recurrent meningeal nerve to cause vaso-constriction to the innervated structures? Does the lesion give rise to proprioceptive impulses which stimulate anterior horn cells to cause somatic vasoconstriction, ischemia and pain? Could this vasoconstriction take place within the cord and lower the threshold of excitation to contribute to a "central excitory state"?

In addition, there are a number of other questions which must be answered with respect to the "central excitory state" and spinal mechanism as they relate to pain - such as specificity or convergence of impulses transmitted to higher structures and the effects of descending controls upon them.

Since 1944, the Foundation for Chiropractic Education and Research has presented data which would indicate that manipulation is effective in relieving pain - and cost-effective at the same time - which results from vertebral dysfunctions. The exact mode of action of manipulation is not known and we must investigate the process itself.

It is recommended to DHEW that research must be aimed at the understanding of the normal and abnormal mechanics of the spine and the effects of joint function on the afferent side of the nervous system. Somato-somatic and somatovisceral reflexes must be clearly understood if we are to ever appreciate the

Secretary Joseph A. Califano, Jr. Washington, D.C. Page Four

mechanisms of vertebrogenic pain and their relief by manipulation.

It is our contention that one cannot research chiropractic only by researching manipulative technique as if it were one modality in a long list of modalities of physical medicine, for it is a whole system of analysis, diagnosis, therapeutics and prophylaxis. Our emphasis is on the unity of the human body, the individual patient. This is perhaps the major contribution we as a profession can make.

Principle II - Opportunities for Young Investigators

There must be the assurance of ample opportunities for truly innovative investigators. It appears to us that the inhibiting effects of age are matched by the suppressing effects of conformity. The young investigator must have opportunity for initiating research. Increasing the small research grant pool for young investigators is one alternative — and in fact, this is one specific step the Foundation has already taken with the initiation of its own mini-grant program. Also, it would be worthwhile to support additional postgraduate research programs, especially at our developing institutions. In addition, it is recommended that the peer review committees acknowledge the genuine research capabilities of even the newest and smallest of our institutions.

Principle III - Interdisciplinary Research

As is obvious by our previous comments pertaining to potential research topics, we advocate interrelationships between basic and applied research as well as among the scientific disciplines. Creative avenues must be found to support these relationships. One way might be to fund additional interdisciplinary seminars with established and young investigators as participants. Also, consortia approaches among institutions must be encouraged, i.e., UCLA Medical Center and the Los Angeles College of Chiropractic joining together to develop a model for the treatment of low back pain.

Principle IV - Effectiveness of the Nation's Health Service

One of the major problems which the chiropractic profession believes should be addressed more adequately is how to educate an individual of his/her own responsibility for health care. Research dollars must be directed into projects that will emphasize preventive measures, rather than disease care. The Foundation believes in holistic health care, early diagnosis, effective treatment at a reasonable cost and the utilization of the most conservative approach feasible.

Principle V - Health Mission of DHEW

The Foundation supports the approach of increasing and restoring the Federal commitment to basic research. We also believe that all Federal research components must accurately assess the new and possibly misunderstood knowledge bases which may offer

Secretary Joseph A. Califano, Jr. Washington, D.C. Page Five

solutions to health care problems and to the attendant costs.

It is recommended that the chiropractic profession be represented on the various advisory committees in order to ensure that the same diversity which DHEW has heretofore encouraged in all phases of professional research will be maintained in the peer-review process. It is only through a creative partnership within the health care community that each of the issues addressed above can be resolved.

We appreciate the opportunity to express our views and suggestions on Federal funding for health research. The Foundation for Chiropractic Education and Research looks forward to continuing opportunities to participate in the comprehensive review of Federal support of health research.

Respectfully yours

Harold W. Phend, Ph.D.

Executive Director

HWP/mb

cc: Dr. Paul Marks

Dr. Donald S. Fredrickson

Dr. Van D. Mericas

Dr. Louis O. Gearhart

DUKE-WATTS FAMILY MEDICINE PROGRAM Duke University Medical Center and Durham County Hospit



August 10, 1978

Mr. Joseph A. Califano, Jr.
Secretary
Department of Health Education &
Welfare
Washington, DC 20201

Dear Mr. Califano:

I was delighted to read a copy of your remarks before the annual meeting of the American Federation for Clinical Research. As a physician committed to research in the area of primary care, I was particularily pleased by what I read as a growing commitment on your part toward support for endeavors in epidemiology, behavioral science and "practical health care quality research". I think you're right on target.

As part of a young, flourishing Family Medicine movement, I also appreciate your concern for creating opportunities for young investigators. I think the time is clearly ripe for the "young squirts" of medicine to grapple with fundamental problems of health services that have been ignored for all too long. You are correct in believing that basic issues of health care quality have been lost in the deluge of technology and glamour of "basic research". With issues of cost containment confronting us, it is increasingly important that we actively pursue research into questions of how to most efficiently and humanely provide health services, critically assessing the impact of the increasingly sophisticated increasingly expensive technology that threatens to enslave us.

I urge you to support research in the primary care specialities of Pediatrics, Internal Medicine and Family Medicine-focusing on issues of quality of care, efficacy of care, preventive health, behavioral and psychosocial medicine and behavior modification. It is no secret to you that the major health problems in this country are not immunologic deficiences and degenerative nervous system diseases but obesity, cigarette smoking, and alcohol abuse. Most patients that seek medical care do not have leukemia but are depressed; most young families do not need genetic counseling services, they need to learn how to eat wisely.

I applaud the concept of developing a long range plan for health research, and most emphatically reenforce your commitment to the concept of a broadly based health research effort. I feel confident that with input from medical researchers from all the aspects of the health service system as well as consumers, a balanced plan is possible. Those of us in Family Medicine research, while lacking in tradition, are fortified with enthusiasm, and look forward to the challenge of providing our country with meaningful answers to its health dilemmas.

Sincerely yours,

Stephen H. Gehlbach, M.D., M.P.H.

Director of Research

Duke-Watts Family Medicine Program

SHG/ds

group Health association of america. inc.



August 1, 1978

The Honorable Joseph A. Califano Secretary, Department of Health, Education, & Welfare Hubert Humphrey Building Washington, D. C. 20201

Dear Mr. Secretary:

This will acknowledge your letter of July 19, 1978, asking for comments on the principles that the Department of HEW should adopt to establish both applied and basic research priorities.

We believe that your proposed multi-year strategy makes a great deal of sense. It is hoped that whatever plan is forthcoming will retain the flexibility to react to new findings as well as new questions while assuring an on-going coordinated approach to some important and basic unresolved issues. Such a strategy should reflect the need for longitudinal studies which are so essential in many research efforts by exploring the possibilities of firmer funding commitments over time in selected as of study. We at GHAA are especially interested in a strategy that wil Pinclude applied problems, especially those affecting prepaid group practice Realth care delivery. We agree wholeheartedly that there should be some relationship between the Federal dollars committed and the current cost of the subject area in terms of mortality, health status, social impairment and economic costs.

An area where the Federal investment could be enhanced is, in the systematic compilation and dissemination of Federally-funded research in progress as well as completed projects. The current situation sometimes lends itself to duplication and unproductive overlap on the part of

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Level three too

the Federal Government as well as the research community. We have found that all too often research results do not readily become a part of the body of knowledge familiar to and utilized by clinicians, educators and others involved in prevention, treatment and training.

We would be pleased if you could forward us a copy of the proposed principles prior to the National Conference to be held at the National Institutes of Health on October 3-4, 1978.

Sincerely,

Executive Director

JC:er1



HEREDITARY DISEASE FOUNDATION

August 10, 1978

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Mr. Joseph A. Califano, Jr.Secretary of Health, Education and WelfareWashington, D. C. 20207

Dear Mr. Secretary:

Thank you for extending to us the opportunity to comment on "A Multi-Year Strategy to Guide the Allocation of Limited Government Health Research Dollars" This is a vast area meriting the most serious thought. I limit myself to just one basic idea.

There are, of course, many very good research proposals in the biomedical field which are unfunded because of budgetary limitations. This regrettable state of affairs has, on occasion, prompted some rather negative thinking. For example, it has tempted some to conclude that we should choke off the number of basic and clinical scientists. It has tempted others to be too satisfied with current ways by which hypotheses and experimental investigations come into being. Since we now have many more reasonable projects than we can fund, little thought is given to procedures by which we can develop scientific questions of even greater merit. This makes little sense either scientifically or economically.

The real problem is to accelerate creativity to the point where we are constantly forced to agonize even more about the many great and exciting hypotheses that exist but which cannot be attended to or answered. As creative as biomedical science is today it could still profit from a shove in that direction. I'm interested in the process by which that result may be achieved and wish to address that issue.

The problem involves two major elements: First, acceleration of scientific communication, and second, advances in interdisciplinary exchanges. In my ex-

Joseph A. Califano, Jr. August 10, 1978 Page Two

perience most biomedical scientists will say that current mechanisms exist to take care of both issues. In my view, they are wrong. Or, more kindly put, they are merely drifting toward solutions. They should operate by design, not drift.

For example, a recent article in Science points out that the drift to greater use of the telephone may do much to replace scientific journals as a mode of communication. With the enormous proliferation of journals and the extended lead time for publication it may well be that personal communication by phone is desperately needed to bring researchers up to date on what's happening. Fine and dandy. But that's limited, often hit or miss, and probably quite narrow. Narrow because mainly the phone calls are between people in very like fields.

What would truly accelerate communication and really bring scientists from different disciplines together on a frequent basis? That's the key question. Key because in this increasingly complex world of research a single discipline may not be effective to get an answer to very complicated questions.

In all likelihood biomedical science has now advanced to a point where three major strengths are frequently required to insure real progress: clinical medicine, basic science, and high technology in fields related to engineering and physics. It isn't enough for rapid communication to occur among like scientists. It must occur on an interdisciplinary basis, must occur often, must occur in small groups, must be free and open ended, must insure a safe environment for speculation, and must invite a novel input for all so that it becomes both a learning experience and an inviting atmosphere for innovation.

The answer to this is the development of small, interdisciplinary Workshops. They should be organized around either a general or narrowly specific field, depending on the "State of the Art". They should include both "resource" personnel to introduce the area for discussion and interdisciplinary participants who devote a full weekend for freewheeling discussion. The size of the group should rarely exceed fifteen (15). These Workshops can be held in various parts of the country to cut travel costs. They are basically quite inexpensive to operate and the values obtained far exceed the cost.

Joseph A. Califano, Jr. August 10, 1978 Page Three

I know all this from hard experience, not theory. Our Foundation operates such Workshops constantly. It is the most valuable tool we have for engendering scientific hypotheses, for recruiting high-level scientists, for advancing rapid scientific communication, and for educating scientists as to the potential contribution to be obtained from related disciplines or even from seemingly distant disciplines.

What we do as a small Foundation has, in my view, wide application, even in government. I do not belittle the holding of large scientific meetings, Symposia, conferences, and the like. I only urge this one creative mechanism which on a cost/productivity basis is hard to beat.

If nothing else I would hope for a real examination of the need to bring medicine, basic science, and high technology together as a unified force in biomedical research. Whether the Workshop idea appeals, or not, the very best payoff will come when these elements are juxtaposed in some meaningful way.

These ideas are sketchy. They surely echo your own concerns and interests as expressed in remarks at the annual meeting of the American Federation for Clinical Research. I merely suggest a specific mechanism and a specific statement on the disciplines which must be united.

Respectfully yours,

Milton Wexler, Ph. D.

President

H. D. Foundation

MW:dv

D. M. GRAHAM 205 ndrth wiget lane WALNUTICREEK, CALIFORNIA 94596

August 22, 1978

Dr. Joseph A. Califano, Jr.
The Secretary of Health, Education & Welfare
Washington, DC 20201

Dear Dr. Califano:

Your memorandum to Professional Societies and Health Organizations concerning the HEW Multi-Year Strategy for Support for Health Research recently came to my attention.

I am a professional member of the Institute of Food Technologists and for many years have been associated with research, education and industry activities in areas related to food science and nutrition. I am interested in your attempts to bring some order into the support of health science research. This is an area in which a great deal of disorganization and confusion exists.

With this letter I am forwarding a copy of a presentation made by Dr. C. F. Niven, Jr., a recent past-president of the Institute of Food Technologists. I have worked closely with Dr. Niven for the past three years and I believe that the ideas which he sets forth in this talk are innovative and will perhaps be of interest to you in your reevaluation of methods of funding for health science as research. I believe that pages 5, 6, and 7 are particularly appropriate to your present area of interest.

I hope that this letter and attached information will be of some value to you.

Very truly yours,

D. M. Graham

D. M. Graham, Chairman Committee on Public Information Institute of Food Technologists

DMG:rs
Encl.

cc: Dr. C. F. Niven, Jr.



INTERNATIONAL CHIROPRACTORS ASSOCIATION EXECUTIVE OFFICES

August 29, 1978

Mr. Joseph A. Califano, Jr. Office of the Secretary Department of Health, Education and Welfare Washington, D.C. 20201

Dear Secretary Califano:

We are responding to your memorandum of July 19 concerning HEW's Multi-Year Strategy for Support for Health Research. The International Chiropractors Association is vitally interested in this subject and wants to emphasize the inadequate attention given to research in the chiropractic area.

Your request for a firm core of scientific knowledge upon which HEW can base policy statements is of particular interest to us. It must certainly be said that such a firm core of evidence does not exist on the subject of chiropractic and/or spinal problems. To support this contention, we have the conclusions of the National Institute of Neurological Diseases and Stroke (NINDS - later changed to NINCDS) from its February, 1975 Conference on The Scientific Status of the Fundamentals of Chiropractic, which was that there was no adequate data either for or against the efficacy of "spin-manipulative therapy". NINCDS' Analysis and Recommendation went on to state that "the Department of Health, Education and Welfare needs to consider both chiropractic and manipulative therapy from the viewpoints of strategy and priority. The fundamentals of chiropractic and of the other schools of manipulative therapy are founded on a century of clinical experience. There are little scientific data of significance from which to evaluate this clinical approach to health and to the treatment of disease. An obvious strategy would be the fostering of biological and clinical research so that answers to the questions of clinical indications and therapeutic efficacy of manipulative therapy can be approached more meaningfully . . .

* * * * * * *

"(NIH should) launch a targeted program of predoctoral and post-doctoral research training of chiropractors (our emphasis) and physicians for careers in research and clinical investigation relevant to matters such as back pain and manipulative therapy. This program should include utilization of the National Research Service Award mechanism and the Research Career Development Award and Academic Award mechanisms."

We wish to state here that there are many studies that indicate the efficacy of spinal adjusting as a health procedure. What we are addressing here is the collection of the type of data in which we understand you are now interested; i.e., "adequate" data, both basic and clinical, gathered under the most rigid of scientific conditions.

We believe that chiropractic colleges should be targeted as the recipients of research funds so that the oftimes adverse political climate does not predoom such a research effort. In our view, attempts were made to undermine the above referred to Conference but thanks to the efforts of those present who were interested solely in the scientific productivity of the Conference, the attempts failed.

The ICA agrees that chiropractic research should march from "basic research to applied research to technology transfer". It is for this reason and others, that we financially and intellectually stimulated the initiation of a basic chiropractic research project at the University of Colorado at Boulder in 1969. We continue to support this project, one that has since received the support of NIH based in part on its scientific merits. More of the clinical fall-out from this project must now be transferred to the chiropractic colleges for further development of clinical trials. From this step can arise the type of data needed for "technology transfer".

The declining support for research and the declining number of young scientists entering the research field must be seriously addressed. A reversal of this trend is essential. It is self-evident from HEW's own information that increased spending on chiropractic research can be stressed.

We believe that the most efficient use of federal research dollars, in the chiropractic area, can be met through faculty exchange programs wherein faculty conducting such research can be exchanged among chiropractic colleges or between non-chiropractic independent institutions and chiropractic colleges. This would result in a rapid expansion in the number of doctors of chiropractic interested in pursuing research as a career.

As to whether the allocation of federal research dollars bears a reasonable relationship to the "basic burden of illness" in America, we feel that the dearth of data on, for example,

back pain reflects poorly on the relationship. Studies clearly indicate that such pain is wide-spread, bringing suffering to as many as 7,000,000 citizens each year. Studies also show that chiropractic care can return such sufferers to productive capacity as much as 300 percent faster than other forms of health care, resulting in less loss of time at work, less pain, and less economic loss to employers. Since the spine is the area of specialized expertise of the doctor of chiropractic, it is logical to expect that the badly needed research in this area be carried out at chiropractic colleges.

The NINCDS Workshop concluded that "a review of studies of the patho-physiology and pathology of spinal root compression is characterized by the lack of available data." For this very reason, and because of the basic chiropractic hypotheses that suggest viseral effects from neuro-spinal corrections, the ICA feels studies should be supported in this area. A beginning has been made in the bioengineering department of the University of Colorado in the ICA-supported research. Basic studies of the effects, both neurophysiologically and neurochemically, of compression of spinal root nerve fibers have been undertaken by Doctor Sharpless and Dr. Luttges respectively. The program has been coordinated by Dr. Chung Ha Suh.

The International Chiropractors Association feels that one of the basic principles upon which research funds should be granted is the extent to which there is patient demand for such a service. For example, the clear need for improved care for back pain sufferers argues for a greater research effort in this area. The more radical forms of care such as chemotherapy and surgery have done little to resolve this wide-spread and ever-growing health problem. Conservative approaches should be researched in greater depth than has been the case in past years.

Perhaps the philosophy that patient demand is not a good indication of health service need -- because the patient is not a professional -- should be reexamined. The American people are creating constantly increasing pressures on the government for improved health services and delivery of those services. Until we answer their demand, we will not be on our way to a full solution.

We wholeheartedly support your first three Basic Principles that you envision would underlie a five-year plan. We particularly encourage you on the third principle; namely, that basic research has to be accompanied by vigorous, thoughtful and, where appropriate, interdisciplinary applications. The chiropractic profession hopefully began a tentative first step in this direction when it encouraged the conducting of the NINCDS Workshop. The ICA, in fact, testified before Congress for the appropriation that directly resulted in the Workshop.

Interdisciplinary work will be necessitated by chiropractic's inclusion in such federal programs as Medicare, federal employees compensation and health benefits programs, Medicaid and any future national health insurance. We had best be developing avenues for such relationships at an early stage. At the research level would seem an ideal place to encourage and refine such relationships, where the politics of the issue, which are sometimes controversial, can be best avoided.

Your fourth basic principle is of special importance to the chiropractic profession. We fully agree that research and the prevention of human sickness has been sorely lacking. The philosophy of "treat the disease" has held sway over virtually all health delivery. More emphasis on how to avoid sickness could arise as a result of your efforts. The chiropractic profession has maintained since its conception that its services would help prevent ill-health. Certainly this concept deserves a high priority on matters to receive research funds.

We hope that your fifth basic principle would include research into the relationship between the spinal column and the nervous system and the role this relationship may have in health and disease.

In conclusion, the International Chiropractors Association supports your effort to shore-up the research efforts supported by the United States government. We feel that research funds should be allocated for chiropractic research because of:

- * The extensive cost of spinal problems to the public both in money and time lost.
- * The present utilization of chiropractic services by the public (studies show that 49% would use such services if they were reimburseable).
- * Your suggestion that all areas of health care should receive research funds.
- * The fact that chiropractic colleges are in a position to conduct research.
- * The need for interdisciplinary and intraprofessional cooperation toward the end of improving our citizens' health.

We lastly urge you to consider the appointment of doctors of chiropractic on decision-making bodies in the National Institutes of Health. Indeed chiropractic services are now involved in health programs that relate to each major subdepartment under your direction. Shouldn't the inclusion of chiropractic be as smoothly integrated into these areas as is possible. The addition of such chiropractic staff would perhaps result in a dramatic improvement in health services coordination.

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We hope these thoughts are responsive to your letter of July 19 which arrived in our offices on July 31. We are prepared to answer any other inquiries you might wish to make of us.

Sincerely,

J. F. McANDREWS, D.C. Executive Vice President

JFM/kb

cc: Dr. Joseph P. Mazzarelli President

> Dr. Andrew B. Wymore Chairman Research Committee



INTERNATIONAL COMMITTEE AGAINST MENTAL ILLNESS P. O. Box 898, A Station - 1990 Broadway, New York, N. Y. 10023

TELEPHONE (944) 359-8797

CABLE: INTCOMMAMI

August 9, 1978

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Hon. Joseph A. Califano, Jr. Secretary Dept. of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

I carefully read your memorandum of July 19, 1978 to Professional Societies and Health Organizations on the subject of HEW Multi-Year Strategy for Support for Health Research, and the accompanying address by you at the annual Meeting of the R. Kusumanto Setyonegoro, M.D., Ph.D. American Federation for Clinical Research. A. V. Snezhnevsky, M.D. Ludwig Tramer, M.D.

> Obviously the five principles enunciated in your address are sound, but what puzzled me is that, particularly in light of the 5th principle - that HEW supported research should support not some but all of the health missions of the Department - the specific earlier references were limited to NIH research and to the area of basic or clinical research.

> A logical conclusion of the 5th principle would suggest that HEW research activities should also encompass research strategy related also to work done at ADAMHA (Particularly NIMH) research in OHD (particularly the Rehabilitation Services Administration) and beyond that, to the extent possible - interagency research such as that performed by the Veteran's Administration, the Labor Dept., etc., where these impact on health or behavioral aspects of populations.

As to clinical research, it makes eminent sense to emphasize the importance of applying knowledge derived from basic research to practical applications

Hon. Joseph A. Califano, Jr. - 2 -

serving health needs. However, it is also important that so-called applied or operational research be likewise enhanced.

For example - in attempting to solve the difficult problem of de-institutionalization of chronic mental patients, much community research is required to point the way to effective alternatives, to determine cost effective and patient effective processes which would maximize the likelihood of sound community adjustment. Research in these areas, it can be argued, is too significant to be overlooked. While the MIMH Research Strategy does provide for such research, my point is that these in turn relate to other HEW research activities and there is the need, as your 5th principle demonstrates, to see that all activities are appropriately integrated.

Sincerely,

Irving Blumberg

Executive Vice President



JOSLIN DIABETES FOUNDATION, INC.

ONE JOSLIN PLACE, BOSTON, MASSACHUSETTS 2215

(617) 732-2400

July. 31, 1978

Mr. Joseph A. Califano, Jr. Secretary Health, Education and Welfare Washington, D.C. 20201

Re: HEW Multi-Year Strategy for Support for Health Research

Dear Mr. Califano:

Having just received your memorandum and the request for "- - - views and suggestions - - " by August 7, I am responding briefly as President of the above institution carrying on moderately major programs in patient care (in this instance primarily those with diabetes mellitus) and in both basic and targeted research, as well as efforts directed toward education at all levels, and in solving the problems of young people threatened with chronic disease.

Frankly, your remarks to the American Federation for Clinical Research on April 29, 1978 were "right on the money", surprisingly so in view of your more visible image as one pushing strongly in the direction of socializing medicine. This is not the place for that issue, as I am most anxious to respond positively to your message related to health research.

If I were trying to create de novo a set of basic principles, I could not establish a more appropriate set of priorities or describe the need any better than you have done. Particularly key to your first principle is the inclusion of "behavior", which I think I recognize as the more modern and probably more appropriate designation of where mental health efforts should be going. This is the realm of science needing so much research and improved understanding in order to prevent obesity, alcoholism, drug abuse, smoking, and perhaps generic to them all the inabilities, relative or absolute, to cope with the stresses of every day living and physical infirmity.

If there is a finite limit to dollar and manpower resources, which we all seem to be believing, despite John Kennedy's thrilling message of almost 20 years ago, then I would support re-emphasis upon a reversal of those "- - sobering facts - - -" last April.

One of the issues with which you dealt only tangentially, and appropriately so in view of the emphasis of your presentation, has to do with the development of person power. As I am sure you are well aware, over the past 25 years the tremendous burgeoning of basic science in the property of the development of medical institutions to educate young investigators, physicians, allied health professionals, etc., so that sizable portions of research monies

and patient care dollars are devoted to education and training. With poorly identified and extremely meager funding mechanisms for the educational process at all levels, little emphasis has been placed upon sorting out what is needed for patient care, for example, from all the testing and teaching needed to educate these hordes of young professionals.

It seems to me your fundamental priority for basic research in biology and behavior is exactly correct. I would like to plea also for high priority being given to person power, training and development, in order to stem the tide away from research and from the teaching of some of our most talented young scientists and teachers in the clinical care field.

Sincerely yours.

Robert J. Bradley, Robert F. Bradley, J.D. President

RFB:skh

Baylor University School of Nursing 3616 Worth Street Dallas, Texas 75246

August 2, 1978

Mr. Kurt C. Habel
Chief, Program Planning Branch
Office of the Director
Department of Health, Education
and Welfare
Public Health Service
National Institutes of Health
Bethesda, Maryland 20014

Dear Mr. Habel:

Thank you for your letter of July 24, 1978.

Enclosed please find a statement of need and related principles for public health research of Hispanics. If you have any questions about this information, please, do not hesitate to contact me.

I would like to be apprised of the plans to facilitate public input for the October 3-4, 1978 conference to be held at the National Institutes of Health. The LATINO CAUCUS of the AMERICAN PUBLIC HEALTH ASSOCIATION is interested in there being Hispanic representation throughout the articulation and related policy development processes.

Thank you kindly for your attention to this request.

Sincerely,

Margarita C. Trevino, R.N., M.S.

Rresident Latino Caucus

American Public Health

Association

cc: Secretary Joseph A.Califano, Jr. Dr. Donald S. Fredrickson

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Enclosure

STATEMENT OF NEED AND RELATED PRINCIPLES FOR PUBLIC HEALTH RESEARCH OF HISPANICS

The response to the memorandum issued by Secretary Califano July 19, 1978 calling for input for the development of an HEW Multi-Year Strategy for the support of health research is being addressed by a preliminary ennumeration of prioritized areas of concern related to critical health needs of Hispanics.

STATEMENT OF NEED

Public health research is needed in (1) demography, (2) epidemiology, and (3) the development of behaviorally-oriented treatment or intervention modalities. Two other areas of concern among Hispanic public health scientists are (1) the protection of consumer rights and (2) the development of Hispanic manpower training programs in the field of public health research.

Research activity is recognized as a fundamental and indispensable element in the identification and correction of some of the disparities in the health status of Hispanics in this country. We urge that the principles that will emerge reflect marked specificity to the promotion and support of valid, reliable, and culturally-sensitive research of Hispanics.

PRINCIPLES

- (1) FACILITATE THE DEVELOPMENT AND SUPPORT OF BASELINE SURVEY RESEARCH SPECIFICALLY DESIGNED TO IDENTIFY AND DOCUMENT SOCIODEMOGRAPHIC, SOCIOPSYCHOLOGICAL, SOCIOCULTURAL, AND INTRAETHNIC GROUP CHARACTERISTICS OF HISPANICS.
- (2) FACILITATE THE DEVELOPMENT AND SUPPORT OF EPIDEMIOLOGIC RESEARCH OF HISPANICS WITH PARTICULAR EMPHASIS ON PREVENTABLE, DISABLING, AND CHRONIC DISEASE ENTITIES.
- (3) FACILITATE THE DEVELOPMENT AND SUPPORT OF RESEARCH EFFORTS TO DESIGN BEHAVIORALLY-ORIENTED INTERVENTION MODALITIES FOR THE HEALTH-RELATED PROBLEMS OF HISPANICS.
- (4) ENSURE THE KNOWLEDGEABLE CONSENT OF HISPANIC CONSUMER-PARTICIPANTS IN ANY RESEARCH ACTIVITY TO AVOID ABUSE ATTRIBUTABLE TO CULTURAL BARRIERS.
- (5) FACILITATE THE DEVELOPMENT AND SUPPORT OF HISPANIC MANPOWER TRAINING PROGRAMS IN PUBLIC HEALTH RESEARCH.



OFFICE OF THE DEAN SCHOOL OF NURSING

Area Code 503 225-7790

Portland, Oregon 97201

UNIVERSITY OF OREGON HEALTH SCIENCES CENTER

August 16, 1978

Joseph A. Califano, Jr. Secretary of Health, Education and Welfare 330 Independence Avenue, Southwest Washington, DC 20201

Dear Secretary Califano:

After reading about you in TIME magazine and various newspaper articles, and then learning that you were interested in developing principles to guide research funding, I grew hopeful about the future of health and health care in the United States. Certainly you would not be bound by tradition or fearful to challenge the unrealistic bondage by medicine!! Your address before the American Federation for Clinical Research was encouraging! Then I read the first draft of principles circulated by Dr. Frederickson. Either you are not the person pictured in your press or your imprint hasn't been yet placed on the health research planning principles. The principles I saw are just more of the same old stuff!

The four categories for viewing National Institute of Health activities represent a medical approach to improving medical care and are not totally applicable to the broader field of health research. Category one, for example, focuses on the disease process and individual response to that process. A health care scientific base would focus on groups as well as individuals, conditions under which health is maintained, etc. The National Institute of Health category implies that health and illness are on opposite ends of a single continuum. This is no longer viewed as conceptually sound. To continue to support research effects along such a framework will result in ineffective use of the research dollar. The resulting programs will bear the same criticisms Congress is now making.

For example, I believe that Principle #1 should speak to the goal of improving health -- not health care! If the focus was on health as a state of being and not on methods of curing disease, (health care), research addressed to health as it interacts with social issues (such as President Carter has spoken to) could receive funding priority.

Your list of invitees for the October 3-4 meeting has apparently not been made public. Hopefully the list includes the scope of professionals concerned with health -- economists, housing specialists, policy analysts as well as nurses, dentists, physicians and administrators.

Secretary Joseph A. Califano, Jr. August 17, 1978

Page -2-

I urge that you take a new look at health research -- one that builds upon current data and forecasts. Listen to Congress and other critics of the disease/cure research emphasis. Generate principles which speak to care, the chronically ill (both young and old), alternatives to hospitalization, self care, prevention and health. This is where the science of health care exists. Let this research lead to application, demonstration, etc.

In terms of your concern for the research physical plant and training the next generation of investigators, I totally agree.

I look forward to reading the results of your October meeting.

Sincerely,

Carol A. Lindeman, RN, PhD Dean, School of Nursing

cc: Senator Mark O. Hatfield Senator Robert Packwood Representative Les AuCoin Representative Al Ullman

CAL/cs



The Living Bank

P O BOX 6725 HOUSTON, TEXAS 77005 • 713 528-2971

August 4, 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education, and Welfare Washington, D.C. 20201

Re: HEW Multi-Year Strategy for Support for

Health Research

Dear Mr. Secretary:

Thank you for including The Living Bank in soliciting input for the above study. We are honored to participate.

As you are aware, The Living Bank is a unique organ and body donor registry. Our purposes are three-fold:

(1) Educating the public about the importance of organ and body donations;

(2) Registering those who desire to become

members; and

(3) When death occurs, referring donations to the appropriate facility closest to the point of death.

With respect to phase (3) above, we maintain 24 hour telephone coverage and a current list of national medical institutions in need of organs and bodies for transplantation or anatomical studies in order that timely referral of donations can be made. Since our founding in 1968, more than 550,000 requests for information have been processed, and members are from all 50 states, the District of Columbia, and many foreign countries.

The United States has some of the most outstanding medical centers in the world where life-saving kidney transplants are being performed; corneal transplants are bringing sight to many blind persons, and other organ and tissue transplants are aiding in the treatment of the severely burned, bone cancer, deaf ... the list is endless! Research is being conducted constantly which is improving upon immunology--so vital to successful transplantation. New on the horizon is pancrea transplant, bringing hope to the diabetic. And who knows what breakthroughs in research will bring about additional medical miracles? It is obvious that the need for organ and tissue donations, as well as bodies for research and teaching purposes, will only accelerate in the years ahead.

Hospitals, organ and tissue banks, and medical schools are all primarily concerned with the recipient and with the research and development of methods of treatment for various medical problems. The Living Bank, on the other hand, is concerned only with the donor and serves as intermediary between the donor and the medical agency or institution involved. As a result, educating the public about organ donation is a major factor in our program. To our knowledge, we are the only organization of our kind in the country. As more and more articles appear in newspapers, magazines and periodicals concerning organ transplantation, our requests for information increase--by the thousands! In December of 1977 Abigail Van Buren referred to The Living Bank as a source for donor information in her syndicated "Dear Abby" column--and we were flooded with some 24,000 letters. She has just printed a special column about The Living Bank, and bags of mail are already arriving. She advises us that we can anticipate some 40,000 letters. (A copy of both columns is attached.) But this is only touching upon the broad education which must occur in order to make it the usual, rather than the unusual thing to be a donor.

When you hold your major conference in October, I think it is essential that organ and tissue needs for transplantation purposes, as well as bodies for research and teaching, be considered as a fundable need for the future. This might take several directions. However, eventually there needs to be a national registry, where a computerized list of donors is maintained, as well as current data concerning medical facilities all over the country allowing for instant referral through a 24-hour telephone service—similar to the service we presently provide.

I hope the above information is useful to you in your planning for this important conference. If you would like any additional information, or feel our participation in the conference would be appropriate, please let me know.

Sincerely,

THE LIVING BANK

Lorraine V. Gress

Executive Director

Enclosures

MANUFACTURING CHEMISTS ASSOCIATION



1825 CONNECTICUT AVENUE, N.W., WASHINGTON, D.C. 20009

ALBERT C. CLARK
VICE PRESIDENT
TECHNICAL DIRECTOR

TELEPHONE: (202) 328-4240 TELEX: 89617 (MCA WSH)

October 3, 1978

Dr. Donald S. Fredrickson, Director National Institutes of Health Building 1, Room 124 9000 Rockville Pike Bethesda, Maryland 20014

Dear Dr. Fredrickson:

These comments are in response to the recent request of Secretary Califano for reaction to his April 1978 proposal to develop a multi-year strategy for the Department of Health, Education and Welfare (HEW) support for health research.

HEW is in a unique position in possessing the potential for considerable effort in advancing the frontiers of knowledge concerning health. This becomes especially important in view of the spate of regulatory and related activity that has diminished the research and innovative capacity of industry and other organizations. The ability of government agencies to devote more of their resources to research obviates the alternative of retardation of man's progress. HEW has substantial facilities for carrying on research within the federal establishment as well as a sizable budget available to it for conducting health research outside the federal establishment.

It is important that some appreciable portion of research effort be devoted to regulatory matters. However, it is also true that a goodly portion could serve to direct regulatory activity into fruitful and technically feasible channels as opposed to devoting much effort to unlikely unproven concepts or theories. While theoretical postulations must not be ignored, we should be utilizing the results of health research conceptually to regulate in directions of what we know, not what we fear.

HEW also has a unique opportunity to use the fruits of its research and its capacity to coordinate the research results developed through other sources to put to rest unwarranted, hysterical claims of severe threats to public health which are not based on fact or even partially substantiated theory. Application of suitable science and research, with knowledge thereof being made available to the public, would serve to allay those upset by the claimed threats. We believe that the Department has an obligation to the public to reflect scientific knowledge and demonstrable facts acting in stability and reassurance to the United States public.

The Secretary makes substantial references to the subject of basic research, but he does not identify any portion with truly exploratory research. Any basic research program would be greatly enriched by an ample portion of truly exploratory research. By devoting the time and talents of some truly creative minds to the pursuit of carefully selective hunches, much can be accomplished of an exploratory character that will greatly enhance the basic knowledge of man on many scientific and health fronts.

We hope that these remarks have been of some assistance, and should you or the Secretary desire, we would be pleased to discuss them with you at further length, at your convenience. We would appreciate receiving a set of the proposed principles for presentation at the national conference scheduled this October at the National Institutes of Health. Thank you.

Sincerely



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Honorable Joseph A. Califano, Jr. Secretary
Department of Health, Education and Welfare
330 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Califano:

Thank you very much for the opportunity to comment on your memo on the future of Federal support for health research.

For 60 years, Maternity Center Association's programmatic approach to the solution of problems in the delivery of health care has been to emphasize the pragmatic and to innovate with demonstration projects. For example, MCA established education for nurse-midwifery in this country in 1931. I attended that educational program when it was in affiliation with Downstate Medical Center. Now, Downstate is its sole sponsor. According to our established pattern, we assisted the system in picking up and implementing a concept which had proved to be useful in improving care. We then withdrew when the program's continuance was ensured.

Such demonstrations have not always been an easy road. As a matter of fact, the Childbearing Center, our most recent project in out-of-hospital births for carefully screened families has encountered a great deal of opposition from both organized and academic medicine. The latter as you know is the professional community which too often is singularly interested in laboratory biomedical research. In a 1977 paper (a copy of which is enclosed) we reviewed our adventures. We set forth therein the hypothesis that the lack of understanding of epidemiologic concepts on the part of clinical practitioners and academicians may be at the root of the intense opposition to our demonstration. Their unsubstantiated belief that the movement to in-hospital birth alone caused lowered rates of maternal and infant mortality is an example of what we are talking about. Therefore, we heartily endorse your recommendation of the role schools of public health could and must play in an overall strategy.

Mr. Secretary, you may not be aware that Maternity Center Association is essentially a nursing administered organization. With the exception of Frances Perkins, its first director, the program development and administration of this national, voluntary health organization has been delegated by the Board of Directors to a registered nurse for about 58 of the 60 years of its existence.

Honorable Joseph A. Califano, Jr. Secretary Dep't. of Health, Education & Welfare Washington, D.C. Page Two August 7, 1978

The point is that nurses have been and should also be responsible for innovation in the health care system to make it safer and more efficient. However there is seldom, if ever, federal or foundation support for nurses or nursing to implement new ideas. Particularly is this true of those ideas which do not have the support of the medical profession. This has been exactly our experience through the years. In addition, in order for our Childbearing Center to be meaningful, we sought reimbursement for families who need Medicaid support. That reimbursement was blocked for 2½ years by the New York City Health Department on the advice of professional groups until New York State took back reimbursement prerogatives. By now we have been in operation for almost three years and are demonstrating that units such as ours can provide safe, satisfying care. Our cost is one third to one half the fees charged in hospital settings.

In developing demonstrations, we are sparked by the verbalized or observed needs of childbearing families. To those needs we fit the most appropriate response in terms of sound and scientifically based theory and practice. I believe that Maternity Center Association has been successful in mounting its programs in prenatal care, parent education, nurse-midwifery education, and prepared childbirth because its program development has responded to families. MCA has had the counsel of its prestigious medical advisory board while being free from the pressures of the organized professions. With its dedicated Board of Directors, MCA functions entirely on privately raised monies, providing a unique opportunity for creative nurses. Were it not for our history of dedicated voluntarism and the pledging of all resources, our Childbearing Center demonstration would never have gotten off the ground. We have had over 800 interested professionals visit our Childbearing Center and ask questions about replication. Few organizations have the resources, independence and courage to take risks of such magnitude. Therefore, I urge you to make monies available for nurse-sponsored action research in economic personalized care.

In addition there is much work needed in basic research in the field of maternity care. This research should be properly carried out by qualified scientists, both pure and applied. For example, while prematurity is our greatest problem in perinatal mortality and morbidity, the true causes of the initiation of labor are not yet known with certainty. It has seemed very poignant to us that apparently there are greater rewards in expanding and intensifying the use of technology developed to keep alive babies born before term, than there is in preventing prematurity. And, as you know, technology drives up the cost of care. For example in the case of the fetal electronic monitor expenditures increase both directly through the cost of the machines and indirectly through the associated increasing rates of cesarean section. I would hope that in the National Conference on October 3 and 4, you will address such questions as how to deal with the "technologic imperative" and how to provide rewards for "unexciting" basic research to the young, brilliant minds who, as you pointed out, are seeking opportunity.

Honorable Joseph A. Califano, Jr. Secretary
Dep't. of Health, Education & Welfare Washington, D.C.

Page Three August 7, 1978

In sum, Secretary Califano, based on the 60 years of experience of MCA and on its record of improving care through developing and implementing pragmatic experiments, we suggest the following:

That you emphasize your plans to encourage dialogue and activity between schools of public health and schools of clinical medicine;

That you consider the role that nurses and nursing can play in providing imaginative answers to some of the Nation's most serious problems in health care delivery; and

That rewards for research in basic physiology be emphasized over the more exotic inquiries into technology and surgicalization.

Again, we are very grateful for this opportunity to comment and would be happy to speak more fully with you or any member of your staff on this topic.

Yours very truly,

Ruth Watson Lubic General Director

Enc.

THE UNIVERSITY OF MICHIGAN

MEDICAL SCHOOL ANN ARBOR, MICHIGAN 48109

BIOMEDICAL RESEARCH COUNCIL

September 18, 1978

Donald Fredrickson, M.D. Director of NIH 9000 Rockville Pike Bethesda, MD 20014

Dear Dr. Fredrickson:

The University of Michigan Biomedical Research Council wishes to respond to Secretary Califano's solicitation for advice about health research planning principles. We understand that these principles are to undergo study and modification at the National Conference on October 3 and 4 and wish to have our views known to the appropriate panel. Our concerns are clearly within the realm of several of those panels, and thus, we have addressed this letter to you.

We strongly endorse the goals of Secretary Califano as it is clear that research in health care delivery and in applied and fundamental research are essential to this nation.

We are, however, concerned about the implications of these principles for the funding of fundamental research. Thus, it is toward the implementation of those principles that we wish to express concern. In our view, this implementation must include the following assurances:

- 1. Strong safeguards must be established to maintain the productivity of fundamental research in the face of mounting pressure from society and Congress toward application and delivery research in the health field.
- 2. Stability and long-range planning of funding for basic research is essential to the productivity of biomedical investigation. The uncertainty and variability of the past has been a significant problem.
- 3. If added effort to increase research in the areas of clinical applications and health services is to be carried out, we urge that this function be funded with additional research dollars and that it not be funded at the expense of current

NIH efforts. Since only 3% of the nation's health dollars go to research, we feel that a significant expansion of that health dollar commitment toward research is required to permit adequate funding of both areas without the sacrifice of the current strengths of NIH.

- 4. We strongly support the record of NIH in maintaining the strength of fundamental research in this country at a time when real dollars available to it have been declining. In part, this has been due to its strong peer review system, the merits of which must continue to be recognized and supported.
- 5. Because of increasing legislative designation of the commitments of NIH, we feel that you, as Director, have not had adequate internal authority and would urge that the Office of the Director of NIH have broader authority for re-programming of funds from one institute to another. We believe that greater flexibility on the part of the Director of NIH would further enhance the health research enterprise.
- 6. Finally, we would suggest that consideration of the administration of additional research funds in the health services delivery and clinical applications areas be considered as an item outside the purvey of NIH. The reason for this viewpoint is that we foresee a combination of such efforts within NIH as being ultimately compromising to the fundamental and applied biomedical research mission.

Thank you for your consideration of these views and for your dissemination of this letter to the appropriate panels of the National Conference on Health Research Principles.

Sincerely yours,

Larry S. Matthews, M.D.

Chairman

Biomedical Research Council



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August 7, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

MDA Executive Director Robert Ross asked me to reply to your letter of July 19 concerning principles for developing a DHEW multi-year strategy to guide allocation of the limited Government funds available for health research. Although much of our experience in the voluntary health sector may not be applicable to Government programs, we are glad to offer our views and suggestions, as requested.

We assume that the proportion of Government funds for health research and delivery of health care would be established by political and other practical considerations; and further, that the funds allocated for delivery of health care would provide for research and development incident to general problems of health care delivery.

We certainly concur with your views expressed on April 29 before the American Federation for Clinical Research on the importance of fundamental research. I would only add that fundamental scientific research is essential to cultural progress in any modern civilization -- no less so than scholarly pursuits in literature, humanities, the arts, or other fields. It seems unnecessary and illogical to argue -- as some observers have done -- that basic research deserves Federal support because it might someday have an unexpected application.

Priority assessment in the competition for Federal funds to support research in a broad variety of fields requires consideration of both technical and social factors. When an affluent country is conducting sufficient basic research to assure cultural progress relative to that in other such countries -- a situation not necessarily extant in the U.S. today -- it can afford to consider questions of emphasis between basic and applied research. Such emphasis should be determined essentially on technical grounds, such as state of the art, in our opinion.

Continued.....

The Honorable Joseph A. Califano, Jr.

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August 7, 1978

However, when it becomes necessary to decide on distribution of Federal research funds for work in various disease categories, social factors -- such as morbidity, prevalence, economics, and politics -- should be considered. It has been said that disease prevalence in the voting population accounts for emphasis on heart disease, cancer, and stroke, compared to birth defects, which are of course prevalent in the non-voting age population. Yet birth defects are probably more destructive of normal family relations, cause more long-term anxiety, and result in far greater loss of lifetime earnings than those other diseases. Federally-supported research programs on genetic diseases of childhood thus would seem to deserve greater emphasis than in past years.

Against the foregoing general background on allocation of research funds. I should like to make two specific suggestions with reference to development of a multi-year strategy on research funding. Although the job market for scientists might indicate a surplus of available personnel, there has always been a shortage of truly creative people to whom we can look for solutions to formidable technological problems such as human disease. These are difficult long-term problems requiring the best available talent at the supervisory and working levels. Under present circumstances of funding for three-year periods, it is unrealistic to expect laboratory personnel -- particularly untenured staff -- to plan their futures around projects that may not exist three years hence. Long before the immediate aims of a three-year project can be completed, investigators must file applications for continuation. I am told that many scientists spend as much as 40 percent of their time in the writing of applications and in other paperwork necessary to maintain financial support of their projects. This is an inordinate waste of effort that would be better spent in the laboratory. If Federal support could be assured for seven years, or even five years, it would greatly contribute to stability and productivity in the laboratory.

Funding of "permanent" jobs for a certain number of postdoctoral research scientists in the universities at the assistant professor level or higher would also be cost-effective in maintaining the continuity needed to solve long-term problems. These jobs would be non-teaching positions comparable to those held by scientists in private industry.

I should like to take this opportunity also to offer a final comment -- on the need for improved science education. The goals we are discussing will be more easily attained with the support of an informed public. As you know, many science-related issues are incomprehensible without some understanding of science. There are also "anti-science" attitudes that complicate

Continued.....

MUSCULAR DYSTROPHY ASSOCIATION, INC.

The Honorable Joseph A. Califano, Jr.

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August 7, 1978

the problem further. Many of our representatives in Government are faced with decisions involving science and technology for which even they are unprepared. Although advisors and consultants are utilized in Washington, there is really no substitute for scientific training. The days when a rounded education could be obtained without some science are long past and this would seem to deserve attention starting at least at the high school level. Because of the many functions and broad scope of DHEW, perhaps this additional observation will be of interest aside from its relevance to public appreciation of the complexities of Federally sponsored scientific research.

We are most grateful for the invitation to comment on strategies for the future of Federal support for health research, and we hope that the foregoing views will be of some assistance in the development of the important program you have initiated.

Sincerely,

M. L. Moss, Ph.D. Director of Research

Development

MLM: jsw

cc: Robert Ross



NATIONAL ALS FOUNDATION, INC.

AMYOTROPHIC LATERAL SCLEROSIS

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August 15, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education & Welfare Washington, D.C. 20201

Dear Sir:

Thank you for your memo concerning HEW Multi-Year Strategy for Support for Health Research. Please forgive our delay in replying. Vacation schedules have delayed our correspondence.

I would like to discuss with you ALS and its priorities at NIH.

As ALS is similar in symptoms and appearance to other neurological diseases, it is considered by many in the medical community to be a model disease - one which merits careful study. It is also the most demeaning, tragic disease known to man and for this reason, too, it deserves the attention of NINCOS.

It was distressing to hear at the Chantilly meetings that Neurology receives one-tenth of one percent of NIH research funding and that Cancer and Heart receive 70 percent of the total amount. Both of these diseases receive enormous financial support from the private sector. I do not mean to underestimate the importance or the incidence of these two diseases. I do, however, want to emphasize the scanty Federal funding of Neurological research with its very broad spectrum of devastating diseases.

ALS receives a minuscule portion of this one-tenth of one percent and I hope we will see some changes very soon. I would like to make the following recommendations:

1. That NINCDS encourage far more Epidemiological research in ALS. NINCDS figures on ALS incidence and prevalence

are inaccurate and should no longer be used by NINCDS in its publications. There are presently in the United States between 40 thousand and 60 thousand cases. We arrived at this figure after we learned of five thousand cases in the environs of New York alone. The NINCDS figure was ten thousand cases in the whole United States. As patient letters continue to pour in, we realize that even our figure might be low.

- 2. That the Public Health Services encourage physicians to list ALS as the <u>primary cause of death</u> when, in fact, the patient dies of ALS not pneumonia or heart failure. Pneumonia or heart failure are in most cases, listed as the primary cause of death in ALS patients. This being the case, how are we ever going to achieve an accurate count of ALS patients?
- 3. When ALS research appears promising, NINCOS should consider programs to assure a continuum of funding. Much excellent ALS research has fallen by the wayside at NIH from lack of funding.
- 4. We would like to see NINCOS pursue the study of nutrition as it might pertain to ALS. There are many pros and cons concerning this and some indepth research could be very helpful.
- 5. NINCOS should make every effort to lure the "cream" of Neurological researchers to investigate the puzzling disease of ALS, with special attention paid to molecular research. Young researchers should be encouraged and supported by the Federal Government to ensure excellence of research in the future.
- 6. We ask that ALS receive the attention it merits and the financial support it deserves from NIH.

On behalf of the National ALS Foundation, Inc., I would like to thank you for this opportunity to be a part of the future planning of NINCDS.

Sincerely,

Bernice Dreesen, President National ALS Foundation, Inc.

BD/sh



National Association for Hearing and Speech Action

814 THAYER AVENUE SILVER SPRING MARYLAND 20910

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The Honorable Joseph A. Califano Secretary Department of Health, Education and Welfare Room 615F Hubert Humphrey Building 200 Independence Ave., S.W. Washington, D.C. 20201

Dear Secretary Califano:

Reference is made to your memorandum, Subject: HEW Multi-Year Strategy for Support for Health Research, July 19, 1978. We appreciate very much the opportunity to provide our views and suggestions concerning the allocation of government health research funds.

Before responding specifically, I believe it would be appropriate to apprise you of the Association's objectives: to promote the interests of persons with hearing and speech handicaps and related disorders, including deafness, by means of enlightened public understanding; stimulation of consumer advocacy; direct assistance to hearing and speech agencies; extension and upgrading of services; fostering needed social action; and launching a program of prevention.

Our ongoing efforts on behalf of the communicatively handicapped have made us painfully aware of the inadequacy of research funds being channeled to that area, especially when compared to the number of Americans affected by hearing and speech impairments, and deafness. For too long, hearing and speech problems have been stepchildren, despite the fact that more people suffer from these disorders than from heart disease, cancer, diabetes, blindness, tuberculosis, multiple sclerosis or kidney disease. The National Institutes of Health acknowledge that hearing and speech problems represent this country's greatest unmet health need, disrupting the lives of approximately one in ten Americans. The effects on the productivity of so many Americans and our GNP are inestimable.

Statistics depict the magnitude of the problem, and it is indeed one of staggering proportions. But statistics do not suffer. It is the communicatively handicapped human being who does.

Children who are born deaf or with severe communicative disorders are condemned to a life of misery. A child cannot grow normally when everything that is heard is distorted, or he hears nothing. For example, his learning, language and speech do not develop and he is shunned by his peers. The fact that hard of hearing youngsters are being branded mentally retarded and sent to a school for retardates is appalling. It happens!

Consider that Americans are living longer and those whose hearing is affected by the aging process suffer longer in a world half heard - or unheard. Due to the expense, they are unable to have a hearing aid so they can hear the words "grandpa" or "grandma." This is indeed a sad commentary considering state of the art technology which permits us to buy battery-operated calculators at the corner store for less than \$10.00.

These problems adversely affect the quality of life for Americans of all ages. They won't go away. On the contrary, unless a great deal more emphasis is placed on research, the number affected by communicative disorders will compound approximately every decade.

It's time for the decision makers to realize that this group of handicapped should and will be heard. In the past, this has not taken place because hearing and speech disorders are not life-threatening or instantly recognizable as a handicap to the same degree as blindness or a crippling impairment. Deafness is silent, painless and invisible. Are these reasons to ignore such a large segment of the American population?

We are acutely aware of the need for an organization with a single voice to coordinate activities and represent the interests of this large segment of our population. There has been fragmentation due to vested interests and the resultant lack of or dimunition in awareness of this group. As our objective stated earlier indicates, we are filling that void. From my vantage point, it appears that there is a similar lack of coordination and effectiveness within the Federal Government with DOD, VA, HEW, EPA, NIH, BEH, ETV and NIMH, for example, having common interests in this handicapping condition but going their separate ways and lacking a single voice and coordinating body. I believe the time has come for this situation to be corrected.

While a separate research institute for communicative handicaps may be considered by some as too much to ask, I believe it is essential, if coordinated, dedicated research and enhancement of services is to be achieved. For example, it is a fact that the largest single preventable cause of hearing loss is exposure to loud noise, but there is no impetus behind research because EPA's ability to increase public awareness is limited due to funds. Simply elevating the status of NINCDS to obtain additional funds is not the answer. Communicative disorders will always be relegated to a low priority with a disproportionately small piece of the research funds pie.

Mr. Secretary, here is an area in which measurable, discernible results can be achieved in a relatively short period of time. The rewards to the handicapped are inestimable. For a group of disorders we can do something about, the time is ripe.

The groundswell of public interest and grass roots support for these handicapped is building rapidly. We recently completed development of the Lions Clubs International "Hearing and Speech Action and Work With the Deaf" program which was announced before 35,000 enthusiastic Lions attending the International Convention in Tokyo last June. As the information filters down, we expect the over 1-1/4 million members of over 32,000 clubs worldwide to overwhelmingly support activities which will mean a better world for this long ignored group. Other civic groups including SERTOMA, Optimists International and Quota Clubs are turning their attention to assistance for the communicatively handicapped.

These demands will not only be heard but will have to be answered and HEW and NIH must be prepared.

I urge your favorable consideration by elevating research in this area to a level commensurate with the number of Americans whose day-to-day living is affected by these insidious disorders. The creation of a new and separate research institute for the communicatively handicapped within the framework of the HEW Multi-Year Strategy will be the most effective way of seeing that the health research needs in this area are significantly met.

Respectfully,

James T. Spencer, Jr., M.D.

President

JTS:1h



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Ruth Ann Terry Oakland, California August 15, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare The Department of Health, Education, and Welfare 330 Independence Avenue, S.W. Washington, DC 20201

My dear Mr. Secretary:

In response to your memorandum of July 19, 1978, regarding Health, Education, and Welfare's Multi-Year Strategy for Support for Health Research addressed to the National Black Nurses' Association, Inc., I am enclosing an overview of several views and opinions collected from varied sources and levels of persons represented in the health care delivery system within our organization.

We are indeed interested in receiving a copy of the proposed principles prior to the October 3-4, 1978, National Conference and look forward to the conference with enthusiasm.

Thank you for the opportunity to respond and for inclusion in making such a major decision.

Respectfully submitted,

(Mrs) Gloria Rookard, RN, PNA

Unia Poakard

Secretary

mt

Enclosure

₱^00 LINCOLN ST. SUITE 704 DENVER, CO. 80203 ■HONE (303) 861-9090



ATIONAL ENVIRONMENTAL HEALTH ASSOCIATION

Joseph A. Califano, Jr. Secretary, Department of Health, Education & Welfare Washington, D.C. 20201

Dear Secretary Califano:

I am particularly sorry I have been unable to respond to your earlier remark concerning funding for health research by H.E.W. I did, however, read through the particular document you had sent many associations and I find no fault with the five principles for government supported research. I am particularly pleased to see your fifth and final principle regarding support of all the health missions of the department, particularly prevention which this association has been stressing for many years.

If this association can assist you or your staff in naming young scientists in various universities conducting health research, particularly in the field of environmental health, please give me a call.

Sincerely,

Lawrence J. Krone, Ph.D., R.S.

Executive Director

LJK/sjh

THE NATIONAL FOUNDATION

MARCH OF DIMES 1275 MAMARONECK AVENUE, WHITE PLAINS, NEW YORK 10605 914 428-7100

CHARLES L. MASSEY PRESIDENT

August 7, 1978

The Honorable Joseph A. Califano, Jr. Secretary Department of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

Responding to your letter of July 19, we are very grateful for the opportunity to share in your planning with regard to the future of health research. Both your letter and your remarks before the annual meeting of the American Federation for Clinical Research have been reviewed and discussed by the key members of our staff. As you know, the issues you raise are central to our own long-range programs, inasmuch as we are faced with similar circumstances and similar concerns, though on a much more modest scale.

We applaud your determination to bring more orderly planning into the health-research picture, though in view of the nature of scientific research, we believe there may be disadvantages in attempting to plan the unpredictable too precisely. We further applaud your recognition that support for basic research has been eroding and that its importance needs to be reemphasized. We applaud, too, your special interest in giving support and encouragement to young scientists just beginning their careers -- as emphasized in your second principle. Our own concern in this area is evidenced by our thriving Basil O'Connor Starter Research Grant program. Most of all, we applaud your recognition of the need, as stated in your third principle, of a vigorous move in the direction of integrative research. It seems that this need is all too little appreciated, even among scientists. We have striven, in our own organization, to encourage the kind of "scientific impresario" you mention who can see the interdisciplinary connections that will help accelerate the forward movement of entire areas of research.

Although our general feeling about your proposal is overwhelmingly laudatory as you can gather from the foregoing, we do have a concern which could be significant, depending on how your principles are interpreted. Our concern is actually one you mentioned yourself, in terms of "tension" between your first three principles on the one hand, and your last two on

the other. The tension could easily enough slide into outright contradiction. For example, the major thrust of your presentation is ostensibly to bring renewed support to basic research -- which most investigators would interpret as biomedical research as they have known it in the past. But there are major ingredients in your proposals that could result in a considerable reduction in the actual money available for that kind of research.

Your fourth principle, for instance, emphasizes that government-supported research must have a "strong orientation toward improving the quality of our nation's health and effectiveness of this nation's heath services." Thus, you seem to be saying that basic research should be more applied, which sounds very much like President Johnson's "more bang for the buck" policy which had the effect of reducing appropriations for basic research.

In describing your fifth principle you say that research should encompass all the health missions of DHEW, including prevention, delivery, regulation, standard-setting and cost-control; and elsewhere you pointedly refer to "health research" rather than biomedical research and also emphasize that you want to include behavior, epidemiological and other study areas under the broad rubric of basic research. So if you were to wind up increasing the overall amount of money available for "basic research," but then included in that definition all these other categories among which the funds would be divided, the net result could be a substantial diminution of money available for basic research as we now think of it.

We are opposed to any further reduction in the support of traditional basic research programs because we feel that basic knowledge in the biomedical sciences is on the verge of important breakthroughs that could have a striking impact on the nation's health in the not-too-distant future. If the nation were actually to cut rather than add to the funds to be spent on basic biomedical research -- in its traditional meaning -- we believe this would not be an economy in the long run (even in the five-year long run) but would rather be seen in retrospect to have been an extravagance. Also, despite any "technical consensus", we trust that in setting up a five-year projection of allocations, the plans would not be so set-in-concrete as to fail to allow sufficient flexibility for following up new and unforeseen results that could bring earlier payoffs in terms of results for the patient-consumer.

We certainly understand that, in view of the limitation of resources, it might <u>not</u> be possible to do everything we might wish -- including all the basic research we would like. But if the intent <u>is</u> to cut basic research, we believe we should frankly say that, and explain our budgetary reasons for it.

As you know, The National Foundation-March of Dimes is a resultoriented organization, constantly looking for the shortest possible route from the basic to the applied. The concerns we express about basic research are in no sense an abstract plea for the support of science-forits-own sake, but rather reflect our conviction that the encouragement of basic research may be the shortest and most economical route to many of the answers we all seek on the public's behalf.

Since the total demand for research funds is far in excess of the amounts likely to become available we would suggest that any increase in appropriations should emphasize the prevention of early death or life-long disability. Our major objective is to help make it possible for children to be born healthy and to grow into productive adulthood instead of becoming dependent on federal, state, and municipal tax-supported services.

It is good that you are proceeding in such a careful manner, allowing your plans to move ahead in several steps, at a pace which allows full public participation. By encouraging open debate and enabling all interested parties to arrive at a reasonable consensus you will assure maximum benefits for the American people.

We trust you will take our remarks in the spirit in which they are offered. We are aware of the size and complexity of the challenge you have undertaken and if there is anything we can do to help make your task easier, we would be pleased to cooperate.

Sincerely,

Charles L. Massev

CLM:oz



National Huntington's Disease Association

SUITE 501 / 1441 BROADWAY / NEW YORK, N.Y. 10018 / (212) 966-4320

August 22, 1978

Mr. Joseph A. Califano, Jr. Secretary of Health, Education, & Welfare Washington, D.C. 20201

Dear Secretary Califano:

Thank you for the opportunity to express the view and concerns of the National Huntington's Disease Association in regard to the principles the Department of Health, Education, and Welfare should adopt as a guide to the allocation of government health research dollars.

The National Huntington's Disease Association is an active consumer organization representing Huntington's Disease patients and their families throughout the United States. Our grass-roots membership comprises concerned citizens as well as those directly involved with the illness.

Huntington's Disease is an inherited, neurological disorder. It is always fatal. Physical symptoms may include involuntary, jerking movements, loss of motor control, and changes in gait. Personality changes may appear, accompanied by loss of memory and decreased mental capacity. As Huntington's Disease progresses, mental deterioration causes changes in speech and memory.

Each child of a Huntington's Disease parent has a 50-50 chance of inheriting the disorder. There is no way of knowing who has inherited the gene for Huntington's Disease until the symptoms appear. The usual time of onset is between 35 and 45, but about 10 percent of cases occur in young people under 20. As there is no positive predictive test, people who are at risk, who have a parent with the disease, may have to wait a lifetime to know if they have been spared.

There is no effective treatment for Huntington's Disease. Some medications used for schizophrenia provide some relief for the abnormal movements. Other drugs may relieve some of the symptoms of depression or other mood disturbances. No drug can treat the loss of mental faculties.

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No reliable figures are available on the incidence or prevalence of Huntington's Disease. Patients are often misdiagnosed. Death certificates frequently do not record Huntington's Disease as a cause of death. Families hide the existence of the disorder. Current estimates put prevalence rates in the range of 4 to 7 per 100,000, although some recent studies suggest it may be as high as 10 in 10,000. Approximately twice the number are at risk for the illness.

Families affected by Huntington's Disease may pay for home care or institutional costs for upwards of 20 years. At the current price of \$12,700 a year for nursing home care, costs can mount to \$200,000 over 15 years. The costs of long-term care for Huntington's Disease patients are so high that health agency personnel sometimes advise the healthy spouse to get a divorce so that the patient can become a ward of the state and become eligible for medical benefits. Tragically, that may be the only way the well spouse can attempt to save to meet the future needs of children at risk.

Huntington's Disease is a family disease. Every member of the family is affected--emotionally, physically, socially--whether patient, at risk, or spouse. And the disease occurs not once, but over and over again in successive generations.

Psychological stress in a family affected by Huntington's Disease can be overwhelming. Because there is as yet no means to test and identify in advance the persons who may be carrying the HD gene, the child of an HD parent grows up in anxious uncertainty regarding the future. Since the disease shows itself so late in life, the question of marriage and fathering or bearing children poses a painful dilemma.

Attesting to this psychological stress is the unusually high suicide rate among Huntington's Disease patients and those at risk. Some authorities estimate it is seven times the national suicide rate--1.3 percent of all deaths in the United States.

As can well be imagined, the National Huntington's Disease Association is eager to see scientific investigation that would lead to a drug to control symptoms, to a reliable screening test, and to an accurate diagnostic tool. However, in consultation with our Science Council, we have come to the conclusion that the basic cause of Huntington's Disease is not yet clear enough for scientific effort to produce these results.

We feel that the most direct path to the solution lies in scientific research into the cause of Huntington's Disease. Once this is understood, we feel sure that a specific treatment, and reliable diagnostic and screening tests will follow. This applies to health-care delivery systems as well--before any effective system can be established for relieving the disorder, its root cause must be understood.

We would be pleased to respond to any request for further information.

Sincerely,

Anne Elsasser

President

NATIONAL HUNTINGTON'S DISEASE ASSOCIATION

National Lupus Erythematosus Foundation, Inc.

A"Non Profit Corporation

5430 VAN NUYS BOULEVARD VAN NUYS, CALIFORN (\$\infty\$ 91401 (213) 885-8787 (88 LUPUS)

August 18, 1978

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Hon. Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

ROSE HERZOG
The National Lupus Erythematosus Foundation is grateful NORMA HOLLAND FOR THIS opportunity to aid in the long range development SENATOR ALAN BOBBINS guidelines for health research activities of HEW.

Our own emphasis has been in the area of basic research, an emphasis we feel should be continued, strengthened and expanded beyond its current level at the National Institutes of Health, through HEW. We are also engaged in information dissemination to the general public and the medical professional; counseling an fund raising.

Basic research developments are the newest and most promising. As a consequence, gains within basic research may prove to be a long-range cost effective approach. It is generally recognized that the goal of eradication of disease, control and treatment of extant disease, and cost effective health care delivery for all citizens may not be realistic with limited health research dollars. It would appear that the greatest emphasis must retain in basic research categories.

Health care delivery should be considered within the context of legislation rather than HEW direction. If this direction is taken, health care delivery systems may not require consideration when establishing long-range plans for NIH.

Among these plans should be the preparation of interdisciplinary reviews to synthesize current knowledge and obviate the necessity for innumerable journals.

Telephonic data banks and informational open lines could be considered as replacement for innumerable meetings.

Utilization of the National Academy of Sciences as an interdisciplinary group to collect and inform all the

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Hon. Joseph A. Califano, Jr. August 18, 1978 Page 2

disciplines regarding advancements appears worthwhile.

Development and funding of more five-year to lifetime research professors engaged in pure research should also be considered as a priority.

Further, the added disciplines covering individual responsibility for health maintenance should not be obscured.

The above, in brief, represents the thinking of the NLEF.

It would be a privilege to consult further and to participate at all levels of the decision-making process. Your solicitation of views is appreciated.

Cordially,

DR. MARLENE ROTHSTEIN Executive Director

MR:pm



National Multiple Sclerosis Society 205 East 42nd Street New York, N.Y. 10017 Tel. (212) 986-3240

August 11, 1978

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The Honorable Joseph A. Califano, Jr.
The Secretary of Health, Education, and Welfare
Washington, D.C. 20201

Dear Sir:

Thank you for your letter of July 19, 1978.

The National Multiple Scierosis Society is in full accord with your intent to develop "a multi-year strategy to guide the allocation of limited government health research dollars." Indeed, we have found it both necessary and desirable to adopt such a strategy for the efficient raising and expenditure of our more limited funds directed to bringing about through research a practical solution to the problems of multiple sclerosis.

As to the principles to be developed by your Department for this purpose, the five principles discussed in your remarks to the American Federation for Clinical Research seem to us to be well-conceived and capable of implementation.

The most difficult decisions will relate to the balance of effort and funding between basic biomedical research and disease-oriented research. Here the Society shares the views expressed by the National Advisory Commission on Multiple Sclerosis which recommended a per capita basis for the allocation of funds for basic biomedical research (see pp. 124-126, Report and Recommendations of the National Advisory Commission on Multiple Sclerosis, Volume Two; DHEW Publication No. (NIH) 74-534).

I would greatly appreciate receiving a copy of your proposed principles for review before the National Conference on October 3-4, 1978, and trust that our Society will have the opportunity to be represented at the Conference.

Sincerely,

Executive Director



NATIONAL PARAPLEGIA FOUNDATION RESEARCH DIVISION

SUITE L-111 4440 N.W. 19th STREET LAUDERHILL, FLORIDA 33313

August 25, 1978



Mr. Joseph A. Califano, Jr.
Secretary,
Department of Health, Education,
and Welfare
Washington, DC 20201

Dear Mr. Secretary:

Thank you for your letter of July 19, 1978 to the National Paraplegia Foundation, which I regret was somewhat delayed in transmittal to this office for reply. Thank you also for the text of your address before the American Federation for Clinical Research.

It is gratifying to know that the Administration has noted and expressed concern for the fact that training and research opportunities for young investigators has been declining and that — despite nominal numerical increases — Federal support for basic research in the health sciences has declined by 19% in constant dollars. It was thus disturbing to note your announcement of a \$93 million budget increase to the National Institutes of Health for fiscal year 1979 — which represents only approximately half the increase required to balance inflationary pressures, and represents an actual additional 3.4% decrease in NIH research funding. Please correct me if I have misconstrued your statement, which I sincerely hope represents a \$93 million increase over and above the \$183 million required to maintain constant-dollar parity.

I applaud the overall strategic principles you have enunciated and accordingly shall confine my comments to the application of these principles to one key area of health research: the neurological sciences.

Lest my remarks be interpreted as being prejudiced by my professional interests and position, I assure you that — as a personal statement — the reverse is true. In 1965, I received a degree in a field far removed from this area — mechanical engineering. During the past decade, however, I have become increasingly aware of the excitement and intellectual challenge of the neurological sciences as the most potentially rewarding field in the human quest for knowledge. This oncearcane area of study was initially opened up and revealed to us in broad new prospectives by techniques and instrumentation deriving from the space—age technology of the 1966 and During the present decade we have been able to observe events in head to be and development, physiology, and

Mr. Joseph A. Califano, Jr. August 25, 1978 Page 2

pathology on sub-cellular and molecular levels heretofore undreamed of. The new science of molecular biology has already given birth to a newer and vital science of quantitative neurochemistry. Our understanding of the growth and workings of that most mysterious of cells, the neuron: the paradigm of ultimate differentiation is rapidly bringing the control of all our bodily functions within our understanding. The interaction between neurons and their surrounding glial cells — once dismissed as "connective tissue" — are now revealed in their fundamental importance. The glia provide an incredibly well-organized and effective supporting "staff" for the highly differentiated "executive" neuron. Further understanding of these interactions are sure to yield vital insights into the interaction of all cells and an understanding of the most basic secrets in the organization of all multi-cellular organisms.

In short, during the past six years work in the area of the neurological sciences has advanced enormously on all fronts and has reached a point where new understanding of growth and function of incredibly complex neurological processes now offers very real and immediate possibilities for the greatest advances in the alleviation of human suffering and disability in the history of medical science. In the specifically neurological area, I refer to killing diseases such as stroke, disabling conditions such as paralysis, aphasia, and many forms of blindness and hearing loss. I refer to diseases that cripple before birth, such as Cerebral Palsy; to degenerative diseases of long and cruel deterioration, such as Multiple Sclerosis and Huntington's Disease, to the correction of mental illness through an understanding of the basic mechanisms of the brain, and to the suffering of intractable pain that exacerbates every other disease to which man is subject. For this, only 6.5% of the NIH budget is allocated.

With all this before us, as you have noted for NIH as a whole -- appropriations to the National Institute of Neurological and Communicative Disorders and Stroke have not only failed to permit expansion of programs but have actually forced reductions, as purchasing power has not kept pace with inflation. Current NINCDS funding provides only 74% of the purchasing power of the Institute's 1972 budget. The Administration budget for the coming year provides for \$180 million for this Institute (again, only 6.5% of total NIH funding). Even with Congressional increases, the appropriation is still not likely to even approach parity with 1972 funding, which would require \$253 million 1978 dollars.

NINCDS funding in the area of prime concern to the National Paraplegia Foundation -- central nervous system regeneration -- has remained constant at a level of approximately \$4 million annually. I enclose a summary of a scientific Task Force Report -- a strategical approach -- commissioned by the Institute on the status of research in this area which could be expected to provide a "cure" not only for

Mr. Joseph A. Califano, Jr. Agust 25, 1978
Page 3

paraplegia and quadriplegia but for the entire range of diseases and disabilities associated with damage to the brain, spinal cord, and optic tract. The full report of this Task Force is available from NINCDS. It is the recommendation of the FOUNDATION's Scientific Advisory Committee that funding for this particular area of research be increased immediately to the level of \$14 million; increasing during the subsequent year to \$29 million, and leveling off at approximately \$39-40 million (with correction for inflation) in the third and succeeding years.

I trust the Department of HEW will give due consideration to these matters in terms of priority allor clons in the establishment of multi-year strategies for support of health research.

Thank you again and very warmest best wishes.

Sincerely,

NATIONAL PARAPLEGIA FOUNDATION

Richard P. Veraa

Director

Research Division

RPV/md

CC:

Mr. Bruce E. Marquis Dr. Dennis Prager Director Salvatore Raiti, M.D.

NIAMDD Project Officer Robert A. Tolman, Ph.D.

Coordinator Richard J. Barth

Assistant Coordinator S. Terry Cole

National Pituitary Agency

Suite 501-9

210 West Fayette St.

Baltimore, Maryland 21201

Area Code 301-837-2552

August 3, 1978

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Mr. Joseph A. Califano, Jr.
The Secretary of Health, Education
and Welfare
Washington, D. C. 20201

Dear Mr. Califano:

I respond to your letter of July 19, 1978. I would like to emphasize a few points of concern.

- 1. Productivity of biomedical research cannot be measured in the same way as it can in business. Cures developed today often result from cumulative research efforts of the previous 10-20 years. It is essential therefore, to view productivity in terms of advances made, articles published, rather than in new cures achieved.
- 2. The orientation of research dollars in terms of <u>diseases</u> such as diabetes, arthritis, cancer, has political appeal but is basically wrong. We cannot buy cures by pouring in more money into a certain disease study. Appropriation of money in terms of diseases means that a lot is wasted while other scientists are deprived of funds to develop ideas which in the long run, may result in curing many disease processes.
- 3. The current tendency is to emphasize <u>animal</u> research. But how and when is that to be applied to the human? Part of the reason for the current tendency is that more projects can be funded and each is also less costly. But the ultimate goal is for more knowledge of the human and funds for such studies are far more difficult to come by. Remember that the old saying "the rat is the biggest liar in medicine" still applies and bears some truth.
- 4. Scientists tend to be dedicated people who spend long hours at work and pondering over problems in great excess of what is demanded of them in terms of the usual work week. Projects extend over several years. If and when such people leave the research area, they do not return. You cannot "turn on and turn off" research at will from one year to the next depending on the economy. Some firm and long term plan for each 5 year period must be adopted. Scientists must have reasonable assurance of a career support, to maintain their commitment and dedication.

Mr. Joseph A. Califano Page 2 August 3, 1978

5. <u>Travel</u>. This is often criticized. But one of the best ways to exchange information and to stimulate new ideas is to have people together, talking and discussing. This is currently achieved at annual national meetings and international ones and this should not be curtailed or discouraged.

The above represent some of my own personal feelings and I hope that they can be of help to you.

Yours sincerely,

Salvatore Raiti, M.D., F.A.C.P.

Associate Professor

SR:mj

NATIONAL OFFICE — Suite 341, National Press Bidg. — 529 14th Street, N.W. — Washington, D. C. 20045 — (202) 638-4396

July 31, 1978

The Honorable Joseph A. Califano Secretary of Health, Education and Welfare Humphrey Building 200 Independence Avenue NW Washington, DC 20201

Dear Mr. Secretary:

Pursuant to your request for suggestions and commentary on the "HEW-Multi-Year Strategy for Support for Health Research," I have requested commentary from the following leaders of the medical and legal professions:

Professor Raymond Dennehy
Dr. Hymie Gordon
Dr. Tom Hilgers
Dr. John Hillabrand
Dr. Mildred F. Jefferson
Dr. Everett Koop
Mrs. Pat Nixon
Professor Victor Rosenblum
Professor Hans Tiefel
Dr. J. C. Willke
Professor Joseph Witherspoon

Your request, having just arrived on July 28, will be acted upon soon, but probably not prior to the August 7 deadline requested. However, I am certain that the expertise of each of the professionals listed above will be invaluable to you and I encourage you to extend the deadline to August 21 on their behalf.

Sincerely,

(Mrs.) Judie Brown

Director of Public Relations

JB/ir

cc: Carolyn F. Gerster, M.D. President

PAN AMERICAN HEALTH ORGANIZATION

Pan American Saditary Bureau, Regional Office of the

WORLD HEALTH ORGANIZATION

525 TWENTY-THIRD STREET, N.W., WASHINGTON, D.C. 20037, U.S.A. CABLE ADDRESS: OFSANPAN

IN REPLY REFER TO: D/63/2 US

1 August 1978

Dear Mr. Secretary:

I am pleased to have this opportunity to reply to your letter of 19 July 1978 concerning a proposed review of your Government's support for basic research. I am also grateful for the copy of the remarks you made before the annual meeting of the American Federation for Clinical Research in April 1978.

I took advantage of a brief trip to Geneva last week and I am pleased to state below both the views of the Director General of the World Health Organization and my own on your very important initiative.

Within WHO, for a good number of years we have had what you call in your letter a "multi-year strategy" which ennunciates specific principles to guide our programmes. This plan includes criteria, approaches and a general programme framework which provides some detail about our principal objectives for the promotion of health.

We have identified a number of major areas of concern, for example development of comprehensive health services, disease prevention and control, promotion of environmental health, health manpower development and the promotion and development of biomedical health services research. Each of these principal objectives is further broken down into a modest amount of detail. I tell you the foregoing to illustrate how useful the World Health Organization has found the process of multiple year planning, and therefore we would indeed be supportive of the process which you are about to undertake.

.../..

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare
Department of Health, Education and Welfare
Washington, D.C. 20201

WHO's research activities are based on the principle that research should be an integral part of health programmes and should contribute to the solution of those problems for which the health programmes have been formulated. Our programmes deal with high priority, socially relevant health issues. We feel that this approach may be useful to you in deciding on research priorities. We would suggest that you consider two types of health issues: one related to the improvement of the health of the citizens of the United States of America and the other related to a contribution from the United States of America to the solution of health problems in the developing world. The latter type of issue conforms closely to the declaration made by you at the 31st World Health Assembly in your capacity as personal emissary of President Carter.

We would hesitate to indicate the priority health issues for your country since this you naturally decide upon yourself, but from our perspective it would seem that this would include the health service delivery system, the training of health and allied professions, the control of environmental pollution, the control of cardiovascular disease and cancer, mental health and the care of the aged. In WHO's research activities fundamental, epidemiological, clinical, operational, social and behavioural research is applied in various combinations required in the search for solutions to health problems. We feel that this principle might be useful for your research activities also.

As for the research endeavours of the United States and partnership with the developing countries, such problems as tropical disease research, research in human reproduction, and common infectious diseases would appear to be highly pertinent.

Finally, we feel it is our role to offer our cooperation to all Member States, and in this regard we have already participated most actively with a number of governments in developing with them what we call a Medium Term Programme for health. Similarly and if you feel that it would be appropriate, we would certainly be willing to make available to you our experience in elaborating this planning process into an effective management tool.

Thank you again for your kind letter, and I shall expect to hear from you if we can be of further service.

Yours sincerely,

Hector R. Acuña, M.D., M.P.H.



PARENTERAL DRUG ASSOCIATION, INC.

WESTERN SAVINGS BANK BUILDING, B AD AND CHESTNUM STS., PHILADELPHIA, PA. 19107
Tel. 215-735-9752

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Washington, D.C.

11 August 1978

Honorable Joseph A. Califano, Jr.
Secretary
Department of Health, Education & Welfare
Washington, DC 20201

Dear Mr. Secretary:

The Parenteral Drug Association is pleased to have an opportunity to respond to your memorandum to professional societies and health organizations relative to the subject of HEW Multi-Year Strategy for Support for Health Research.

The Parenteral Drug Association was founded over thirty years ago by a group of educators and scientists as a non-profit organization dedicated to the advancement of the science and art of parenteral technology and to the dissemination of information relative to parenteral drugs, sterile products and related processes. The PDA consists of more than 1500 members representing the parenteral drug manufacturing industry, the academic community and related material suppliers.

An important objective of the Association is the cultivation and maintenance of cooperative relations with government agencies and departments and to originate and participate in cooperative enterprises with them. As a corollary, the Association sponsors and encourages research in these areas.

The PDA supports the five principles outlined in the Secretary's remarks before the Annual Meeting of the American Federation of Clinical Research and in particular the fourth principle, "government-supported research must have a strong orientation toward improving the quality of our nation's health and effectiveness of this nation's health services".

The PDA, through its Research Committee and attendant task groups, is currently engaged in research in the following areas: optimal particulate matter counting, radiation sterilization,

- continued -

Secretary Califano

11 August 1978

identification of extractables from elastomeric closures, steam sterilization validation, critical physical and chemical properties of elastomeric closures in conjunction with the U.S. Pharmacopeia, limulus amoebocyte lysate studies and other research projects. We believe these are projects that are worthy candidates for your health research support.

We trust the foregoing has been helpful and that you will consider the Parenteral Drug Association as a scientific and technical resource available to you in support of the principles enunciated supra.

Sincerely,

Frederick J. Carleton

President

SCP:emg



DEPARTMENT OF NEUROLOGY COLLEGE OF MEDICINE MEDICAL CENTER 50 NORTH MEDICAL DRIVE SALT LAKE CITY, UTAH 84132 801-581-6871

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1 August 1978

Mr. Joseph A. Callifano, Jr. Secretary of Health, Education & Welfare Washington, D. C. 20201

Dear Mr. Callifano:

I have read with great interest your speech to the annual meeting of the American Federation for Clinical Research, given on April 29, 1978, which accompanied your request for suggestions on how to allocate federal support for biomedical research. The following are a few thoughts on this matter which you might find useful.

First of all, I believe that the American people should be better informed of the wonderful tradition of medical research that has been established in this country with their tax dollars. A tradition of supporting "good science" has been established by application of the peer review system, and great advances have been made, as you stated in your talk. However, because of an absence of any rational scientific policy and a reactionary "crisis" system of funding, programs of investigation and training are often started and then stopped because of dramatic changes in priorities. It is not possible to develop training programs for neurophysiologists, biophysicists, bacteriologists, etc. on demand in order to serve some perceived current need. A policy is necessary which will define areas in which sustained financial support must be given, in order to develop depth in basic science and clinical disciplines essential to furthering our understanding of the biomedical world. At the present time large numbers of young biologists and physicians are leaving the academic community for lack of support. In my own field of neurology a large black hole looms ahead, because very few young people have chosen to remain in research or in academic practice. Because I have been unable to obtain any funding for my personal research interests, I can not support these young people, and my effectiveness as a research neurologist is severely impaired. Support for young people in applied and basic biomedical areas must be provided, and the "feast or famine" method for supporting departments and divisions in our medical schools should be adjusted.

Clinical scientists, those investigators who work with patients, find it extremely difficult to obtain research support through the usual means. A clinical investigator most often comes off as a dilettante in comparison to some one who spends full time at the laboratory bench. New ideas concerning disease mechanisms and innovations in the area of treatment do occur to such clinicians, and their proposals are very often reviewed by basic scientists with very little or no understanding of the clinical problems involved. Dr. Fred Plum, President of the American Neurological

Association, has suggested the formation of a division of the National Institutes of Health devoted to clinical applications of biomedical knowledge, so that clinicians interested in research might find easier communication with the granting agency, resulting in greater research activity in the clinical setting. An air of despondency now exists in most medical schools. Most of us work in medical schools because we feel that it is a special place one can act on new ideas. I would hope that medical schools will not become giant health care businesses with an adjunctive teaching and minimal research function.

In my own setting I have attempted to develop applications of physics and chemistry to the specific biological problems with which I am working. I have colleagues in the Departments of Physics, Chemistry and Engineering. New ideas have evolved from these relationships, and we hope to receive support for the projects which have been formulated in the very near future. The benefits of these interactions have emphasized to me that within any given university are many individuals who could benefit greatly from contact with each other and with the community in which they live. Such contacts are much too infrequent, and most often the community has little or no idea about what goes on within the university. I believe that each university should have an interdisciplinary research council where scientists of every discipline can bring their problems for a broad-based discussion. A small handout or booklet should be published on a monthly basis, where problems are presented in brief form, so that other scientists can respond and establish the necessary contact.

Better methods for community education concerning biomedical research activities taking place within the university should be established. As a result of major cutbacks in funding, many universities are attempting to obtain more local support for research and service projects. This has been a healthy move, which should be nurtured and perhaps supported in some way by the government. For example, I have established a multiple sclerosis clinic which is supported by The Multiple Sclerosis Society, around which research proposals are being developed and which is served by a social worker and nurse practitioner partially supported by federal funds. Unfortunately, as a result of a recent cutback in federal funding, we will lose our nurse practitioner and possibly the social worker as well. I believe our clinic is a viable focus of interaction between the medical school and the community and has stimulated a number of very prestigious investigators to focus upon the problem of multiple sclerosis, which I consider to be a major health problem in this country.

In the present climate it is very difficult to find support for truly new ideas and approaches to biological and medical problems. Without a long bibliography and years of experience in a given research area, it is next to impossible to obtain any funding. At the present time there is no mechanism by which a really good new idea can be funded. Finally, I have always felt that the inclusion of all funding for health, welfare, education and research activities under one budget was very misleading to

the public. This plus occasional articles in the newspapers on exotic, unusual research projects the scientific merit of which can not be understood by the average person, creates a very bad image. Funding for research and development should be sufficiently identified and separated so that no confusion exists in the public mind.

There are many places where savings can be made in the use of health care funds. I agree that ambulatory care facilities should be increased, and regulations applied to insurance payments for out-patient treatment should encourage out-patient management. Savings in other areas can come through more effective health care planning, so that centers of expertise for performance of certain types of studies can be developed. The concept of two full service hospitals across the street from each other competing for the health care dollar reaches certain limits when both hospitals buy C-T scanners, expensive electrodiagnostic equipment, etc.

These concepts have wandered very greatly in content and only serve to emphasize the complexity of the problems that we are facing. I hope that some of these thoughts will be of help to you in your deliberations.

Sinceraly yours,

Professor of Neurology

JHP/ma

PHARMACEUTICAL MANUFACTURERS

PRESIDENT

WASHINGTON, D.C. 20005

August 4, 1978

The Honorable Joseph A. Califano, Jr. Secretary Department of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Secretary:

We were interested to learn from your memorandum of July 19 that the Department of Health, Education, and Welfare is planning a National Conference to explore HEW Multi-Year Strategy for Support for Health Research. We appreciate the opportunity to submit our views and suggestions on the principles to be discussed at the Conference on October 3-4, 1978.

We are fully aware of the importance and timeliness of the Conference since HEW policies and strategies in health research have an important bearing on other components of the health research community. As you know, the pharmaceutical industry makes a major contribution to the health research effort in the United States and worldwide. Our latest figures for expenditures by PMA member firms reveal that in 1977, approximately \$1.5 billion was budgeted for basic and developmental research for drugs, devices and diagnostic reagents. By any measure, this is a substantial and impressive investment by the private sector. It is essential, therefore, in our opinion, that HEW integrate this vital and unique contribution to health research in its planning strategy.

It is to the great credit of both HEW and industry that their respective strategies in health research have been complementary, rather than competitive. HEW support of fundamental biomedical research and the training of biomedical research personnel have been a sine qua non of the present national health research effort. It has provided important research leads and cadre of biomedical scientists. Reciprocally, industry has provided experimental drugs, devices, and diagnostic reagents that have been pivotal in many of the research projects sponsored by HEW. On balance, the present partnership between government and industry in health research has been highly productive, and should be maintained and strengthened.

We believe, as a general principle, that HEW health research strategies should definitely take into account their impact on other elements of the health research community. They must also recognize the unique and substantial contributions made to health research by these non-government constituencies. It would be of great value in the forthcoming Conference to include a segment on the role and strategies of HEW in health research from the perspective of the private sector. To do otherwise would, we believe, be a serious omission in the Conference and in the development of an HEW strategy to maximize the benefits to be derived from a well-integrated national health research effort.

There are several outstanding executives in the drug industry who, in our opinion, are recognized authorities in health research and who could provide this perspective. I offer for your consideration the names of William N. Hubbard, Jr., M.D., President of The Upjohn Company; W. Clarke Wescoe, M.D., Chairman of the Board of Sterling Drug Inc., and Gerald D. Laubach, Ph.D., President of Pfizer Inc. None of them has been contacted by me, but I shall be pleased to do so if you are interested in their participation.

We applaud this forward-looking initiative on the part of HEW, and wish you success in the Conference.

Sincerely yours,

Joseph Stetler

cc: Dr. Frederickson



The University of Texas Southwestern Medical School

Division of Plastic Surgery

Kenneth E. Salyer, M.D., Chairman Donnell F. Johns, Ph. D. Ronald W. Atkins, M.D. Robert J. Demuth, M.D. Hamlet T. Newsom, M.D. Ralph E. Holmes, M.D. Kristine Bennett, M.D.

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Joseph H. Little, M.D.
Alfred R. Antonetti, M.D.
Teresa M. Elliott, M.D.
Carlheinz Tizian, M.D., Fellow

September 1, 1978

Mr. Joseph A. Califano, Jr. Secretary, Department of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Califano:

As Chairman for the Plastic Surgery Research Council, I am responding to your request for suggestions on the HEW Multi-Year Strategy for Support for Health Research.

It has been my feeling that plastic and reconstructive surgery has not had proper funding or support of many vital research projects. This is in part related to the fact that many of our studies overlap into other areas of medicine or dentistry. As a specialty, plastic surgery involves research into tumors, immunology, transplantation, microsurgery, bone substitution and regeneration, and many other areas of a biological origin. Since these areas coincide with existing programs, our own research endeavers are diluted and further are not evaluated by clinical surgeons, but rather basic scientists who may not be entirely familiar with the clinical ramifications of a surgical research project.

For this reason, I would suggest the formation of a National Institute of Surgery, comprised of surgeons for evaluation of research projects within the whole field of surgery. Since most basic scientists are not familiar with the research problems surgeons must contend with, this concept is particularly important in the treatment of patients as well as generating interest in investigating clinical areas as they relate to our care of patients.

Should you desire additional information on this, I or one of my colleagues would be happy to discuss this further with you, supplying any specifics you might need. I hope this is helpful to you in developing the HEW Multi-Year Stratgey for Support for Health Research and I look forward to hearing from

Mr. Joseph A. Califano, Jr. Page 2 September 1, 1978

you should you have any other interest in this concept.

Sincerely,

Kenneth E. Salyer, M.D.
Chairman, Plastic Surgery Research Council

Professor and Chairman

Division of Plastic Surgery

KES:mtr

cc: Peter Randall, M.D., President

American Society of Plastic and Reconstructive

Surgeons

Victoria Doretti, Educational Coordinator



POPULATION REFERENCE BUREAU, INC.

1337 CONNECTICUT AVENUE N.W., WASHINGTON, D.C. 20036 (202) 785-4664

Culty 11. 1978

The Honorable Joseph A. Califano, Jr. Secretary
Department of Health, Education, and Welfare Washington, D. C. 20201

Dear Mr. Secretary:

In reply to your memorandum dated July 19, 1978 regarding HEW Multi-Year Strategy for Support for Health Research, the Population Reference Bureau and professional members of the staff are very much in favor of basic research of the type presently conducted by the World Health Organization through its many resources in developing countries and through the National Institute of Health Program.

I appreciate having the copy of your remarks before the Annual Meeting of the American Federation of Clinical Research, and I look forward to being kept up to date on your efforts in this regard.

Sincerely yours,

Robert M. Avedon President

RMA: nm

SECTION OF BIOCHEMISTRY, MOLECULAR AND CELL BIOLOGY

CORNELL UNIVERSITY

WING HALL, ITHACA, NEW YORK 11853

N.Y.S. College of Agriculture and Life Sciences
A Statutory College of the State University
COLLEGE OF ARTS and SCIENCES

DIVISION OF BIOLOGICAL SCIENCES

September 29, 1978

Dr. Donald S. Fredrickson Director, DHEW Public Health Service National Institutes of Health Bethesda, Maryland 20014

Dear Don,

I was asked to attend your conference on Health Research Principles as a representative of the American Society of Biological Chemists. Since I made previous commitments for October 3 and 4 I cannot come, but I was asked to submit comments. I should like to emphasize, however, that I am making these comments as an individual member of our Society. I have not discussed the matter with our Council.

Response to the five principles

I would like to discuss first, as briefly and concisely as possible, the five principles outlined by Secretary Joseph A. Califano, Jr.

- 1. I fully agree with the first and most basic principle as outlined and with the plan to give serious attention to renewal of the physical research plant.
- 2. I fully agree with the second principle and I shall make a suggestion as to how we could develop opportunities for young investigators.
- 3. I fully agree with the third principle and I shall make a suggestion as to how we could develop better connections between basic and applied research as well as between research disciplines.
- 4. The fourth principle is, as the Secretary realizes, controversial. In fact it appears to contradict the concept of principle 1 which calls for the freedom to do research topics "that are not immediately relevant." The apparent contradiction and controversy could be eliminated by some minor revisions in the wording of the principle and in the planning of its application As it stands, the fourth principle appears to require that all government-supported research must have a strong orientation toward improving the quality of our nation's health. Moreover, the first sentence raises a question for which there is no answer. Basic research that has no "impact whatsoever" on health problems of today may have a great impact on health problems of tomorrow (see principle 1, page 8).
- 5. I agree with the sentiment of the fifth principle that we should not single out certain diseases for excessive support, neglecting others. I agree that we should re-examine the distribution of the resources.

Recommendation

- 1. How much money should we assign for basic research? I recommend a simple formula which may require difficult reorganization of the funding process. All basic research of high quality should be supported regardless of whether the application is channeled into the Cancer or Heart or General Medical Sciences Institute. I do not know how this kind of flexibility can be achieved legally. We should aim at some mechanism which avoids the funding of second-rate science in one category while applications approved with high priority in another category cannot be paid.
- 2. What is first-rate research? We should continue to rely on the peer-review system to make the decision as to which research should be supported. I am aware of the shortcomings of the peer review system it involves human beings yet it is the best we have.
- 3. I believe that we could do better in the area of communication. I fully concur with the recommendation made in the discussion of the third principle that we should "seek new ways of supporting those who understand and can make interconnections..." Among our young scientists there are a few who are very much concerned with "relevance" and they could be "turned on" to apply their talents to the task of making connections. There is need for more teaching in this area. Awards and fellowships could be instituted. Perhaps a small conference of scientists, who are interested in developing ideas in this area, would be a first step (Dr. S. Udenfriend and I have collected names of possible candidates for such a conference).

I share President Carter's concern about our nation's future research capacity and I agree that the young generation of scientists is a key issue. Unless we can create a better image of science and scientists than presently shown on the television screen, we shall not be able to halt the present downward drift discussed on page 4 of Secretary Califano's speech. We need to educate the public as to what science is really like and reverse the antiscience atmosphere. I take the liberty of enclosing the copy of a short editorial entitled "Science for People" that will appear in "Trends in Biochemical Sciences."

With best wishes for this conference.

Sincerely yours,

Efraim Racker Albert Einstein Professor of Biochemistry

ER/jc

cc: Dr. Mildred Cohn Dr. Russell Hilmoe

Note: Dr. Racker is away on a lecture tour and asked me to send this letter unsigned. He wanted to make sure it reached you before the conference.

RES

PRESIDENT:

M. MICHAEL SIGEL, Ph.D.
Deparmeent of Microbiology & Immunology
School of Medicine
University of South Carolina
Columbia, SC 29208
803 777-7928 or 7105

PRESIDENT-ELECT:

SIGURD J. NORMANN Professor of Pathology University of Florida Box 275 JHMHC Gainesville, FL 32610 904 392-3741

SECRETARY:

MARIO R. ESCOBAR, Ph.D. Medical College of Virginia MCV Station—Box 106 Richmond, VA 23298 804 786-9153 or 0575

TREASURER:

PIERSON J. VAN ALTEN, Ph.D.
Department of Anatomy, Microbiology
Immunology
University of Illinois Medical Center
P. O. Box 6998
Chicago, IL 60680
312 996-3552

EDITOR, J. RETICULOENDOTHELIAL SOC.:
QUENTIN N MYRVIK, Ph.D.
Bowman Gray School of Medicine
Winston-Salem, NC 27103
919 727-4471

COUNCILORS:

STEPHAN E. MERGENHAGEN, Ph.D. (1978) Chief, Laboratory of Microbiology & Immunology National Institute of Dental Research National Institutes of Health Bethesda, MD 20014 301 496-4178

THOMAS M. SABA, Ph.D. (1981)
Professor and Chairman
Department of Physiology
Albany Medical College of Union University
Albany, NY 12208
518 445-5651

JANE I. MORTON SIEGEL, Ph.D. (1980) Division of Immunology Department of Medicine University of Oregon Health Sciences Center Portland, OR 97201 503 225-8399

ROBERT R. STRAUSS, Ph.D. (1979) Albert Einstein Medical Center Philadelphia, PA 19141 215 329-0700

HERMAN FRIEDMAN, Ph.D. (1978) Albert Einstein Medical Center Philadelphia, PA 19141 215 329-0700

MEMBERSHIP COMMITTEE CHAIRPERSON: JANE I. MORTON SIEGEL, Ph.D. Division of Immunology Department of Medicine University of Oregon Health Sciences Center Portland, OR 97201 503 225-8399

INTERNATIONAL RELATIONS COMMITTEE: HERMAN FRIEDMAN, Ph.D. Albert Einstein Medical Center Philadelphia, PA 19141 215 329-0700

RETICULOENDOTHELIAL SOCIETY

ADMINISTRATIVE OFFICE

4720 MONTGOMERY LANF

BETHESD 4001 .

3070654-3080

August 18, 1978

The Honorable Joseph A. Califano, Jr. Secretary
Department of Health, Education, and Welfare
Washington, DC

My dear Mr. Califano:

The June Newsletter of the Federation of American Societies for Experimental Biology carried the text of your speech delivered at the annual meeting of the American Federation for Clinical Research, April 29th, in San Francisco. In this speech, you expressed interest in hearing from leaders of the health research community as well as from other interested parties. As President of the Reticuloendothelial Society and as a Department Chairman within a newly-created medical school, I should like to take advantage of your invitation.

At the outset, let me say that I fully subscribe to the principles outlined in your presentation. I agree with all five, but I believe that it is the third, fourth, and fifth priciples that are of utmost importance for the reconciliation of conceptual controversies and for the search for new approaches to satisfy the needs of untargeted research on the one extreme, and delivery of better health-related services on the other. I consider the third principle pivotal, as it speaks of interconnections. As a scientist and administrator, I have attempted to establish links and build bridges between diverse disciplines, departments, and other groups, and I believe that the third principle should be extended beyond the forging of interconnections between basic and applied research by encompassing academe, research institutes, industry, government and, in particular, the public. I mention the public because the explosion in scientific knowledge, while improving society's life and comfort, has also frightened the layman just as it has boggled the mind of the scientist. The wealth of scientific information is outpacing the means of communication, even among specialists, and certainly between specialists and generalists, and has made communication between scientists and the public all but spurious. You speak of convening a rational conference on health research planning. This the warmin is not likely to resolve the problem of intercommunication. What is needed is the creation and sustainment of long-range intercommunicative networks for

exchange of ideas, needs, and aspirations. These interfaces should occur within institutions and among groups, regionally and nationally. The groups that come to mind are academic institutions, private research institutes, industry, health-related associations, state agencies, federal agencies, and the public. Among the academic institutions should be included the whole gamut of colleges, medical schools, and schools of nursing, dentistry, veterinary medicine, engineering, journalism, public health, etc.

The need for scientific consortia within universities or among universities and industry has been recognized and there have been created, in the past, both formal and informal collaborative groups. Unfortunately, although many of these start off with good intentions, they often run aground for a variety of reasons. One reason is jealousy which transcends the rivalry inherent in the life of units deriving their revenues from the same source or the friendly competition between scientists in the same field or the envy of the minimally funded scientist at seeing large sums committed to narrow targets. This type of super jealousy arises when one component of a group comes up with a major breakthrough and the others regard it as a threat to their status. Scientific status is jealously guarded in this period of the dwindling dollar and decreasing research support. Another reason is the reluctance on the part of industry to commit major investments for projects which might result in discoveries of patentable commodities, since a liaison with an academic institution supported by government funds would put restrictions on acquisition of patents. Since consortia and other collaborative groups are composed of humans, they are, of necessity, subject to the usual human frailties of suspicion and distrust which become intensified by rivalry. But it is probably the absence of participation of an informed public that has added to the erosion of interactive programs which depend on ever-increasing financial support. The public, which should be a partner in the scientific enterprise, is usually left out entirely despite the fact that it makes this enterprise possible by direct or indirect contribution of funds. What is worse is that the public is not informed sufficiently of the workings of science and, in fact, is misinformed by screaming headlines and oversensationalized stories.

It is therefore my firm belief that the five-year plan or a ten-year plan should include a thorough consideration of the logistics and strategy of creating interfaces between and among the groups cited above. I intend to do this within my capacity as Chairman of the Department of Microbiology and Immunology at the University of South Carolina School of Medicine. The department is only six months old and the school has just celebrated its first birthday, and I hope that I shall have the opportunity to advance some of the ideas

that I am presenting to you. It is my fervent hope that your office will see fit to encourage a broader and deeper committment of this nature. I realize that neither your office nor any human force can eliminate jealousy, envy, or suspicion, but the government can help to reduce the factors which either generate or intensify these foibles.

I can see two basic approaches. One is by improvement of exchange of ideas, needs, and aspirations through interfaces mentioned previously, and the other through a series of incentives which would encourage these exchanges and better interactions. The nature of incentives will require considerable thought and I realize that some (tax exemptions or patent rights) will require congressional action, while others (special kinds of grants) may be fashioned by your Department.

There are two other matters which I would like to mention at this time, with respect to manpower and cost of research. We are taining thousands of PhD's who are facing a shrinkage in job opportunities. Inflation and diminished rates of increase in levels of research funding have been blamed for this situation. These are valid explanations but, in my opinion, there is still another cause and that is overspecialization which is a natural consequence of the tremendous growth in knowledge making it necessary to concentrate on a relatively narrow area. There is, therefore, a need for a bold revision in our thinking regarding graduate and postdoctoral education. Without compromising the finely tuned training of specialists in molecular biology or genetics, it should be possible to develop highly attractive training for creative people in the fields of clinical laboratory medicine and public health. These people would be in a position to advance the quality of research in these areas, making it even more attractive to future generations. Some element of versatility should also be considered. This may help in the creation of scientists and administrators with capabilities to build links and establish interfaces.

As regards cost of research, I honestly believe that much more could be accomplished both in basic and applied research, as well as in the delivery of better medical care, if there were a reversal in priorities of funding allocations. At the moment, it would appear that much too much money is spent for administration, especially administration that has only peripheral relevance to research, utilization of research, and application of research.

I trust that you will consider some of my thoughts in connection with the long-term plans.

Very Sincerely,

In Unique Sigel, PhD President

MMS:cmp

National Retinitis Pigmentosa Foundation, Inc. Rolling Park Building 8331 Mindale Circle Bahimore, Maryland 21207 78011655 1011

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EXECUTIVE DIRECTOR

Demus 1 Harrensmoe

RP Foundation

Childen have so much to see. And they should all have a chance to

August 7, 1978

Mr. Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Califano:

In addressing your memorandum concerning HEW Multi-Year Strategy for support for Health Research, it is very difficult to be objective when deeply involved in a specific health problem. The need for some kind of over-all plan is obvious. The limitation of this plan to five years or the development and implementation of such a plan raises the question of priorities.

In your enclosed remarks you outline five principles which would be considered in your strategy. You make mention of directing research dollars to the "disease of the month." One of the most important statements you made, which is perhaps the key to establishing an effective plan, is to question whether the health research effort bears a meaningful relationship to illness.

There are unfortunately many worthy causes. However, some are definitely receiving preferential treatment - sometimes out of proportion to the need for help, while others equally deservant, are almost ignored. Retinitis pigmentosa is a case in point. Because of the difficulty in identifying many of those affected due to the insidious nature of the disease, it is impossible to pinpoint closely the incidence. Certainly it affects at least between 100,000 and 300,000 individuals in this country alone.

The disease is hereditary and often leads to total blindness, but the means of identifying the gene has thus far eluded researchers. Recently scientists have been able to isolate a human gene (see enclosed article) which may be a tremendous breakthrough to all genetic diseases. Research dollars are desperately needed to explore this new technique and apply it if possible to diseases such as RP.

Finding the cause of RP and other inherited diseases is paramount in their prevention. Extensive research in the bio-chemical nature of the disease, the effect and assimilation of certain vitamins, and the importance of nutrition is basic; and the need to test findings in a clinical, scientific manner is imperative.

Another health area that is sorely neglected with regard to retinitis pigmentosa and other allied diseases is service. Where are the low vision clinics, orientation and mobility centers, genetic and psychological counsellors which are so necessary to aid those affected? There are isolated, scattered centers where excellent service is being given; but these are few and far between.

When one considers the amount of dollars the government must spend to assist persons who are blind, the logic in spending more money in an area where blindness may be prevented, treated, or cured seems obvious.

To identify the RP gene, to determine what causes the defect, to develop a treatment or cure, and to give services to the hundreds of thousands affected in this country and in other countries all over the world will involve many competent researchers who need financial support.

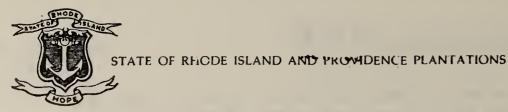
The RP Foundation strongly supports a plan that will help the realization of this goal - not only for retinitis pigmentosa, but for many other diseases ravishing humanity. We welcome the opportunity to participate in the development of such a strategy and hope to be included in the results of this plan.

Sincerely,

Dennis L. Hartenstine Executive Director

DLH: jce

encl.



Department of Mental Health, Retardation and Hospitals DIVISION OF MENTAL HEALTH 600 New London Avenue Cranston, R. I. 02920

August 11, 1978

Joseph A. Califano, Secretary Department of Health, Education, and Welfare Washington, D.C. 20201

Dear Mr. Califano:

The Rhode Island Department of Mental Health, Retardation and Hospitals, Division of Mental Health, applauds the Administration's intentions to place a new emphasis on research in federally funded programs.

Particularly encouraging is the attention paid to the dimension of behavior in your recent address to the Annual Meeting of the American Federation for Clinical Research. Your mention of a commitment to multi-disciplinary research teams and your reference to applied research, imply, it seems to me, a holistic view of man and a conviction that motivational and emotional dimensions of behavior have profound influence on health.

May I strongly urge that a consideration of sociological and psychological variables be included in the development of a Comprehensive Plan for basic research, and the National Institute of Mental Health, and the State Mental Health Research Directors, Division of the National Association of State Mental Health Program Directors be included in plans to develop a research plan.

Sincerely.

Dennis E. Angelini, Ph.D.

Assistant Director

DEA: tmg

cc : Carol Mowbray (cf attached)

The Robert Wood Johnson Foundation

P.O. Box 2316 Princeton, New Jersey 08540 (609) 452-8701

August 4, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education and Welfare South Portal Building 200 Independence Avenue, S.W. Washington, D. C. 20201

Dear Mr. Secretary:

Your letter to David Rogers on federal support for health research arrived just as he was leaving for vacation and I agreed to prepare a reply. Of necessity, what follows represents solely my own thinking. However, Dave and I frequently discuss the issues involved and I am aware of no significant difference between us. Understandably in addressing so enduring a subject I am to some extent guilty of plagiarizing myself.

As I see it, there are two major problems. The first is how to make wise decisions of the allocative sort for the types of research familiar to us now. The second is how to develop an institutional framework to permit us to mount a research attack on the transmedical problems such as those listed in your fifth principle in the San Francisco talk. The first problem is tough, but one can see how to approach it; the second problem is considerably tougher and the approach is not clear.

The first two principles (and to some extent the third) of your San Francisco talk last May relate to the allocative problem. What is involved here is a set of judgemental decisions as to the present and short-term feature of competing fields.

A principle implicit here is that just because in the last analysis the decisions must be judgemental they are not made capriciously; the process used must be perceived as fair.

I mention this because even in your first two "unexceptional" principles there are problems. Specifically the intergenerational competition will require a most thoughtful approach. We have two conflicting needs -- stable long-term support so basic research can be pursued and the need to maintain a free entryway for new young investigators. These come into conflict once it has become necessary (as it clearly has) to make the allocations within an essentially fixed appropriation from year to year. However, despite the difficulties, we do now have ways of approaching such problems. It is the

second problem -- how to obtain research on the transmedical issues -- that will require a good deal of ingenuity and wisdom.

By "transmedical" I mean those problems such as the health problems of the frail elderly or some of the problems mentioned in your fifth principle. These are the problems in which biomedicine "owns" only a part of the problem but unless the biomedical part can be satisfactorily managed, the problem as a whole cannot be successfully attacked.

My major reaction to your fifth principle and to the fourth as well, is not one of disagreement, for, in fact, I agree; my reaction concerns something else, namely the institutional framework that would be employed. For I have become deeply convinced that the particular institutional framework must fit the overall program's purpose and that it is a serious mistake to attempt to handle research of one type through a framework designed for another.

In order for us to obtain some notion of what would be involved, it is necessary, with some assertion of the obvious, to look at what energizes the biomedical research system now. This system has immense flexibility and quick reactive capacity to new problems provided they present as logical extensions of what is under study. This great flexibility is attained largely by what might be termed intellectual decentralization in that the system as a whole is broken down into a very large number of related but intellectually quite independent units, a unit frequently being no more than a single person. These many units or research workers are curious, imaginative, and highly self-disciplined individually, but if one were to look at them as a total group — the group would appear undisciplined or at least unorganized. And this is the way it should be, because it is this intellectual decentralization that energizes the entire system and makes it work.

To obtain the rich creativity of scientific research we have to accept the fact that the assignment of the research worker to a particular research question or problem sector is by and large a selection made by him. What is more, he seldom makes this self-selection on the basis of the needs of society; he makes it for more personal reasons such as his interest in the total field of which his question is a part, the facilities he is able to call on, his own strengths and weaknesses with respect to particular techniques and similar considerations. I do not wish to seem to imply that our biomedical scientists, as citizens, lack social consciousness; on the contrary they are usually among the more socially responsible of a profession with a long tradition of meeting the needs of society. But what I am saying is that the process of self-assignment is in effect a selfish choice in the sense that a great musician or painter makes the selfish choice that he will, indeed he apparently feels he must, create through his particular medium to the exclusion of most other considerations. This holds for biomedical scientists working in government as well as for the others.

It is this system, operated in government principally through the National Institutes of Health, that has given us the splendid scientific achievements of the past 30 years, but it is not well adapted for the organization of a research base for many of the issues listed in your principle five. The question we now face is how can we harness this immense creative force for "... all the health missions of the Department" without weakening the force in the process.

Broadly speaking, the government biomedical institutions have three instruments whereby to support research: an apparatus for identifying a problem and bringing it to professional and public attention; an intramural laboratory and field research capacity; and an appropriation for the financial support of an extramural research and development program. The last-named can also involve contracts as with the chemical industry. For all practical purposes, however, the only one of these three instruments available to the federal biomedical institution to get action in what presents itself as a wholly new problem sector is to try to hasten the process whereby an idea has "come." Not the idea that represents the solving of a problem, but the idea that a particular issue could now become the basis of an intellectually lively research program. The biomedical arm of government cannot really "order" that research on an emerging problem sector be done; neither is it apt to get very much of what it seeks by using what, in effect, would be the bribery of suddenly making available large funds for the purpose. It can really only use the financial inducement after a question has gotten itself identified, characterized, and supplied with people who wish to study it.

The principle I would like to suggest is that the particular institutional arrangements through which a research program is organized and maintained can be all-important to the success of the enterprise and must fit the nature of the particular problem. Consequently, if it is desired to organize research programs in newly emerging and novel problem sectors, it is necessary to invent a special institutional framework for the research activity of each sector.

Except for a few central features, I shall not try to describe in any detail the various types of institutional arrangements that might fit the quite diverse needs of a research base for health care delivery; regulation of drugs; and cost control. Common to them all would be that instead of the intellectual decentralization that makes the classic form of research system so strong, ways would have to be found for various groupings. The people who "own" the problem would have to be brought into contact with those who might conduct productive research on it. And this contact would have to occur in rooms other than an auditorium and be far more than a two-day meeting, three times a year sort of thing. It might have to include joint working sessions held regularly over a substantial period of time for the purpose of identifying the actual questions needing study. It would be the intellectual "closeness" of the investigator to the problem "owner" that would have to be fostered -- something almost the opposite of what makes the classic biomedical research system so great. Given this sort of need, it would seem that government in-house research with a new set of institutional arrangements with the extramural research world would be the first possibility for careful examination and trial.

I realize that I might seem to be ignoring the present NIH in-house biomedical research. In my judgement it is of the highest quality, but it is a great part of the classic biomedical research system. The NIH does not, as it stands, represent a suitable institutional framework for the newly emerging and novel problem sectors of your fifth principle. Clearly it could become so, but whether it would be wise to do so is in itself a large, complex, and separate issue.

One way of looking at our past four decades would be to say that the magnificent achievements in biomedical science have come from two paralleling subsystems: one, the classic biomedical research conducted laissez-faire, that has led to such great understanding of the mechanisms of disease; and the other, sharply oriented research conducted in industry that has led to the greater part of our effective interventions. This complementary system has worked productively so long as the laissez-faire part could expand almost at will and the total system did not have to take outside factors very much into account. Now the situation is different and we must find ways both to adapt and to spread the strength of biomedical research into wholly new areas.

I am extremely pleased that you are leading a stand on these problems. I know I can speak for David as well as myself in saying that whatever it is in our power to do we wish to do -- you have but to call on us. With kind regards,

Sincerely,

Walsh

Walsh McDermott, M.D.

WMcD:dm

cc: Dr. Donald Fredrickson

Dr. David Rogers



VISITING NURSE SERVICE of SUMMIT COUNTY, INC.

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JOAN L. ANDREWS EXECUTIVE DIRECTOR

August 14, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare The Department of Health, Education, and Welfare 330 Independence Avenue, S.W. Washington, DC 20201

My dear Mr. Secretary:

Recently the news media has been inundated with articles and news releases expounding the concerns of the administration for the rising cost of health care.

It has also been called to my attention that you are embarking on a major effort to redefine and/or distribute the monies allocated for medical research over a five-year period. To this end, we who are involved in home health care delivery in Akron, Ohio, have prepared several documents that we feel would be valuable in helping you make a decision to consider research in the area of home health care as a viable, cost effective adjunct to hospital care and institutionalization of our elderly and infirmed others.

Please accept the enclosures as a token of our concerns. I have taken the liberty of enclosing curriculum vitae of two individuals who have an abiding interest in the direction of home health care specifically, the quality of care and cost containment in health care for all Americans in general. They would be valuable resource people, should consideration be given to this area.

Thank you for your attention.

Very truly yours,

Atria At

(Mrs) Gloria Rookard, RN Manager of Patient Services

mt

Enclosures



THE UNIVERSITY OF ROCHESTER

MEDICAL CENTER

601 ELMWOOD AVENUE ROCHESTER, NEW YORK 14642 AREA CODE 716

SCHOOL OF MEDICINE AND DENTISTRY . SCHOOL OF NURSING STRONG MEMORIAL HOSPITAL

September 13, 1978

Dr. Donald Frederickson Director, National Institutes of Health Department of Health, Education and Welfare Building 1, Room 124 9000 Rockville Pike Bethesda, Maryland 20014

Dear Dr. Frederickson:

I have seen a copy of the letter recently forwarded to you from Mary E. Conway, Dean and Professor, University of Wisconsin, School of Nursing, Milwaukee, on behalf of the group of Principal Investigators and Project Directors of HEW funded research grants. I certain y support the comments/ suggestions made in that letter. I have further specific comments and suggestions for your consideration.

As both a nurse and behavioral scientist interested in the application and further testing of basic social science knowledge to problems of health and illness, I am concerned at the underrepresentation of behavioral science research in the organizational and funding patterns of NIH. More and more we recognize that progress in health prevention and management of chronic illness depends on extending our knowledge of successful alternatives in day-to-day orientation to preventive health practices and management of chronic illness by the population at large, of patients' views of health/illness, of provider-patient interaction, and of institutional climates that foster health. The scope of knowledge needed in clinical applications extends much beyond controlled clinical trials of drugs or health services research as currently defined.

Much of the significant behavioral research arplied to successful management of clinical problems which are consequence of disease and patient-client-institutional variables affecting this successful management has been carried on by nurse-research scientists. This is increasingly the case. Indeed, the development of such knowledge is the strongest mandate of our profession.

In the development of NIH Research Planning Principles, I urge that stronger consideration be given by way of organizational and funding principles to the role of behavioral science and, in particular, nursing research. Such consideration

ought, at minimum, to include expansion of expert nurse scientist representation in review of proposals and as recipients of funding in behavioral science areas already existant in the NIH organization. A far better climate for research would be to organizationally recognize and fund clinical nursing research as a part of the NIH research structure. Currently, nursing research must be conducted in an extremely restricted way from either a manpower (Bureau of Health Manpower, Division of Nursing) or service (nursing in the NIH clinical center) base. The potential for nursing's contribution to expansion of clinically useful research is great. I hope that this potential can be recognized within the new principles.

Thank you for your consideration.

Madeline Helmeet

Sincerely,

Madeline H. Schmitt, R.N., Ph.D. Associate Professor of Nursing and Sociology; Director, Clinical

Research Development Grant

MHS:ph

cc: Mary E. Conway
Dr. Henry Foley
Dr. Doris Bloch

TUFTS UNIVERSITY SCHOOL OF MEDICINE NEW ENGLAND MEDICAL CENTER HOSPITAL

HAMIRISON AVERUE. BOSTON, MASSACHUSETTS 02111 (617) 956-5648

Robert S. Schwartz, M.D. Director

Janine André-Schwartz, M.D.
Bernard M. Babior, M.D., Ph.D.
Eugene M. Berkman, M.D.
Syamal K. Datta, M.D.
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DEPARTMENT OF MEDICINE HEMATOLOGY SERVICE

August 7, 1978

Secretary Joseph A. Califano, Jr. Department of Health, Education and Welfare Washington, D.C. 20013

Dear Mr. Secretary:

Congratulations on your speech to the American Federation for Clinical Research. The strategy for health research you outlined impressed me as thoughtful and well-reasoned. Indeed, the formulation of such long range plans is in itself encouraging.

I want to point out a problem, which, if uncorrected, will become serious. I refer to the dramatic decline in the number of physicians now entering fields related to health research.

You may be aware of this shift. Recent figures indicate that the number of physicians engaged in health research has been reduced by 50% during the last 5 years. This decline is reflected by a sharp decrease in first-time applications to the NIH for research grants and fellowships from physicians. A similar trend is evident in applications to private agencies. For instance, in the last cycle of applications for research grants to the Massachusetts Division of the American Cancer Society, only one-third of the requests were from physicians.

The net effect of this development is a replacement of physician-investigators by individuals with the Ph.D. degree. Ironically, this trend appears at the very time the research community is called upon to translate the results of research into health care. Such "technology transfer" cannot be achieved without an adequate force of physicians engaged in health research.

An inevitable conclusion is that many of the important goals outlined in your speech will not be fullfilled unless the present situation is corrected.

The reasons for the declining numbers of physicians who choose careers in health research are complex. However, you must be aware of certain federal policies that have been contributory. Foremost

Secretary Joseph A. Califano, Jr. Page 2 August 7, 1978

among these are those regulations that discourage the training of physicians in research. These policies include the intimidating "payback" clause, the low stipend offered on fellowships and the decimation of training programs. Currently, physicians who accept NIH fellowships receive a lower stipend than they would as hospital residents. Already burdened by debts incurred as students (a factor that does not apply to the Ph.D.), most young physicians are reluctant to aggravate their precarious situation by agreeing to a cut in their income by acceptance of a research fellowship. Let me stress that, in my experience with these highly motivated young physicians, the issue is not avarice but survival.

I strongly recommend that HEW review its policies with regard to physicians in health research. An active program of recruitment should be formulated. If funding is a problem, certain other NIH programs (such as center grants, which shift dollars away from the training of physicians in health research) should be revitalized and the burden of proof of efficacy should be placed on trainors, not trainees.

I sincerely hope that the matters discussed in this letter come to your attention. Indeed, should it be desired I am willing to come to Washington to discuss this very serious problem with you or one of your assistants.

Sincerely,

Robert S. Schwartz, M.D.

Director, Tufts Cander Research Center Chief, Hematology Division

Professor of Medicine



137 NORTH FRANKLIN STREET HEMPSTEAD, NEW YORK 11550

July 27, 1978

Secretary Joseph A. Califano Jr. Department of Health, Education and Welfare Washington DC 20201

Dear Secretary Califano:

I am responding immediately - and as shortly as possible to your memorandum of July 19, received here on July 27. I have especially taken note of the list of five health issues on the first page of your remarks before the American Federation for Clinical Research. The first one of those is abortion and the most obvious must in this area is to identify and move in all possible ways (and I mean all) to reduce the need for abortion to as close to zero as possible. In a speech I gave two or three years ago before the graduation of the Syracuse University Medical School, I stated bluntly that, for a public health person (which I am), abortion is a gross medical immorality. In other words, if health practice were successful, with very few exceptions there should be no unwanted, unneeded or unfortunate pregnancies. It is in this area that our great failure lies, and I faced this problem in my eleven years as Medical Director of the Planned Parenthood Federation, because of lack of motivation of women to practice birth control. Now we are facing this in our young people.

Because of the grim mortality and morbidity figures (including the prematurity that leads to retardation that leads to dependency) in pregnancies in women under eighteen, I have tried to persuade the American College of Obstetricians

SIECUS BOARD OF DIRECTORS. Alan P. Bell, Ph.D., Chairperson; Wardell B. Pomeroy, Ph.D., Past Chairperson, Morton Sontheimer, Vice-Chairperson, Deryck D. Calderwood, Ph.D., Vice-Chairperson, Richard A. Chilgren, M.D., Vice-Chairperson; Larry P. Scott, Treasurer; Frank E. Taylor, Secretary, Pauline M. Carlyon, M.S., M.P.H.; Michael Carrera, Ed.D., Haskell Coplin, Ph.D., Judith R. Falk, M.A., Evalyn S. Gendel, M.D., Harold I. Lief, A.B., M.D.; Rev. James A. Sielkes, M.Div., Rev. Leon Smith, Ed.D., J. Robert Moskin, M.A., Gilbert M. Shimmel, Ed.D., M.P.H., Mette Strong, Mary S. Calderone, M.D., M.P.H.; President

and Gynecologists to make a simple statement, for which the statistical supporting evidence is clear: "Pregnancy in any woman under eighteen is, regardless of her marital or socioeconomic status, physically undesirable." I have found that even though obstetricians and gynecologists agree with the statement, they do not wish to subscribe to it officially.

Finally, then, we have to confront the mess we're in regarding the sexual behavior of young people under the age of responsibility. We know that this is the resultant of a great number of highly complex socio; anthropological and technological factors. If we are willing to admit we should also recognize that it has been happening in the absence of carefully thought out sex education programs, whether in homes, churches or schools. If the public would allow research in this field, we could take a national probability sample of twelve year olds and find out exactly what they know about sex, what their attitudes are about it, where they got their information from, what else they would like to know. kind of survey has not been possible because of public refusal to allow such questions to be asked of children. Yet in our office we daily receive anguished letters from teenagers (fifteen hundred in two weeks because of the bare mention of our name in a publication called Co-ed) asking agonized questions springing from ignorance. I attach one such list for your information.

I do not believe that the schools should be the locus for sex education. The real sex education happens well before the child ever gets to school, in terms of the kinds of information passed on by parents, but more in terms of their own attitudes about sex and sexuality and their roles in life. Generally it is a total blank on the whole subject with which parents send their children into the schoolyard, where they will then begin their sexual mis-education.

In expidemiological terms, considering teenage pregnancy in the light of an epidemic - really a pandemic - we see cohort after cohort of incoming susceptibles joining the ranks of the teenagers exposed to pregnancy out of sheer

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If we are to reduce the need for abortion to zero in this age group, we must devise means to immunize these susceptibles between the ages of one year and twelve years. How to do it? Not with the schools, but with the parents. A strong drive to educate parents in what is at stake in their children's lives, the toll that ignorance takes and the steps that parents must therefore take to get into communication with their children about sexuality and lower this ignorance level - that is our real job. Churches can help by placing this information into the moral context of each particular religious community. This is of vital importance. By the time children get to school then, schools will only have to reinforce what the parents have already done, and provide such course work as is needed to underpin the information that has already been Nothing a school can do should ever negate what the parents have done that is good and positive; but it can serve to rectify errors of omission and comission that parents have unwittingly made. In all this, parents must be helped to be participants in full.

Only in this way can preventive medicine begin to combat the high toll of pregnancies in women under eighteen, and their aftermaths that are so totally undesirable and costly, in spiritual, emotional, and physiological as well as financial terms.

Sincerely yours,

Mary S. Calderone, M.D.

President

Enc. Copy of letter with questions received by SIECUS 1/25/78

Society For Epidemiologic Research

September 13, 1978

MEMORANDUM TO: Office of the Secretary, HEW

SUBJECT: HEW Multi-Year Strategy for Support for Health Research

- 1. This memorandum is the reply to one addressed to Professional Societies and Health Organizations, which I recently received on the above subject.
- 2. The views, concerns and suggestions which are herein expressed develop: from my associations with the Society for Epidemiologic Research, the International Epidemiological Association and the Research Committee of the World Federation of Neurology; and from my roles as referees of original publications in the Journal of the National Cancer Institute and the American Journal of Epidemiology plus membership on such committees as the Epidemiologic Studies Review Committee for the National Institute of Mental Health and the Clinical Trials Review Committee for the National Heart, Lung and Blood Institute.
- 3. The decline in Federal support for training in public wealth in general, epidemiology, demography, biostatistics and allied disciplines has been dramatic and indeed unfortunate since the Nixon administration's withdrawal or lessening of this support.
- 4. Resultingly, in most areas of public health, there has seen a precipitous paucity in the needed personnel to research, and yze, interpret and administer questions of universal importance to health.
- 5. Only with the use of such biomedical researchers as epidemiologists, clinicians, demographers and biostatisticians can our Government fully and responsibly address itself to the existing and mounting health needs of our country.
- 6. The public's realization of and reaction to this need will become even more pointed, I feel, if some form of national health insurance is eventually legislated.
- 7. It should be noted that such programs as Medicare, and Medicaid have provided data bases and potential experimental designs for much needed medical research in many disease and behavioral areas. These include aging, nutrition, exogenous factors in cancer development or prevention, and cultural determinants of patient's seeking, utilizing and benefitting from health resources. Such areas as these should be exploited for benefits of all Americans since the results of such research can only serve to make for a healthier society and probably a lowered expenditure for many health services and facilities.

- 8. Further, there are research leads and topics which defy the approval of the usually composed peer-review-groups, but which may prove to be of high scientific merit. Researching these unpopular topics, too often, has to be done surreptitiously if at all. Accordingly, within the proposed "multi-year strategy for support for health research" should be included some mechanisms for contending with unpopular research hypotheses, leads and topics.
- 9. I am indeed proud that the President has "directed a new emphasis on basic research in Federally supported science programs".
- 10. Finally, epidemiologists, biostatisticians and other public health researchers and officials, as I do, must eagerly await the institution and outcome of this multi-year strategy to guide the allocation of limited government health research dollars.

Andrew J. Killen

ANDREW Z. KELLER, D.M.D., M.P.H. Chief, Epidemiologic Research Veterans Administration 151G, VARO

THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY, INC.



W. MITCHELL SAMS, JR., M.D. SECRETARY-TREASURER

Department of Dermatology North Carolina Memorial Hospital Chapel Hill, North Carolina 27514

7 August 1978

The Honorable Joseph A. Califano, Jr.
The Secretary of Health, Education, and Welfare
Washington, D.C. 20201

Dear Sir:

This letter is in response to your letter of 19 July 1978 concerning review of Federal support for basic research. I am enclosing a document entitled, "Suggestions for Improvements in the Process of Funding for Biomedical and Behavioral Research" prepared by Peyton E. Weary, M.D., Chairman, Department of Dermatology, University of Virginia School of Medicine and a member of the Board of Directors of the Society for Investigative Dermatology. Dr. Weary has had a major interest in this problem for some time, and I believe that this presentation represents some new, logical, and worthwhile approaches to the problem.

On behalf of the Society, I wish to thank you for requesting our input.

Yours sincerely

. Graham Smith, Jr., M.D.

President Elect

cc: George F. Odland, M.D., President
W. Mitchell Sams, Jr., M.D., Secretary-Treasurer
Peyton E. Weary, M.D.

SUGGESTIONS FOR IMPROVEMENTS IN THE PROCESS OF FUNDING

FOR BIOMEDICAL AND BEHAVIORAL RESEARCH

I. PROBLEM AREAS

- A. While certain killer diseases are able to capture the imagination of the public and generate thereby substantial legislative support, the suffering of mankind is probably more related to the chronic degenerative and non-fatal processes which maim, cripple and cause untold suffering for millions over a period of years. The quality of life has been neglected in comparison to the quantity of life in terms of support for biomedical research.
- B. As a general rule, economic costs of illness (both direct and indirect in terms of loss of productivity and family disruption) closely parallel the true burden of illness in terms of suffering, since man is willing to spend the necessary funds to alleviate his suffering.
- C. Little effort has been expended to relate the allocation of research funding to economic indices. There are obvious imbalances in research funding which have been produced by political pressures exerted on Congress and translated thereby into biomedical research funding. These are particularly high-lighted, if one attempts to translate the approximate percentage of both direct and indirect costs to society of various disease categories and relate these to research expenditures on these diseases. This is a simple exercise because the latest economic indices are those drafted by Dorothy Rice and Barbara Cooper for the year 1972. If one relates these costs to research expenditures for 1977, either by institute or by categorical expenditures for selected disease within in institute, substantial discrepancies become apparent. For every dollar of economic loss to society, the following sums in cents were devoted to research:

cancer, 4.7¢
neurological, stroke, communicative and eye disease, 2.0¢
diabetes, endocrine, metabolism, nutrition, 1.8¢
mental health, 0.8¢
heart, lung, and blood disease, 0.7¢
kidney and urological disease, 0.4¢
arthritis and bone, 0.3¢
skin, 0.3¢
digestive disease, 0.2¢

If we look at the economic impact of biomedical research (the cost-benefit ratio) there is probably more benefit to be derived in terms of cost effectiveness by improving the quality of life than by expending the quantity of life. Extension of the quantity of life will in large measure simply prolong the period of dependency of the relatively less productive segment of society, while improvement of the quality of life will restore to productive and useful pursuits those who can contribute most to the advancement of society.

B-278

- D. While man's search for longevity and innate fear of death will mandate continuing substantial expenditures for those diseases which kill, there must be increased emphasis on research for those diseases which disrupt and reduce productivity. The funds which may be saved in terms of health care expenditure by reducing morbidity and economic losses from the crippling diseases could more than offset the funds which might ultimately be expended to find ways to extend life.
- E. Significant research opportunities do not always parallel either the life extension potential of the discovery nor the economic consequences in terms of improved productivity. It is clear that much basic research will have far reaching consequences well beyond those originally intended. There must be a mechanism to stimulate the long-range potential of certain basic discoveries and provide suitable support for those engaged in such fundamental pursuits.
- F. Well-conceived research by competent investigators in whatever discipline will usually be more rewarding than hastily prepared and ill-conceived research generated in response to congressional mandates by which substantial funds are suddenly made available for specific areas of research. In general, the priority scores which are earned by each research grant proposal, through the process of peer evaluation, more closely reflect the competency of the investigator and the potential utility of the results than any other method of mensuration currently available.
- G. In the process of research support allocation all four factors, economic burden of illness, societal pressures, research opportunities and potential research utility must be counterbalanced in some reasonable manner, perhaps on a formula basis, to provide:
 - a.) stability without which productive research will inevitably suffer
 - b.) gradual reduction of unrestrained societal pressures which have so distorted the balance of research support as to create substantial imbalance.

I. POSSIBLE SOLUTIONS

A. Stability of Funding

There are three possible rational formula-based approaches to create overall stability in funding for biomedical and behavioral research:

1. The Priority Score Approach:

If the congress were to adopt a principle that all competing grants for extramural support with priority scores less than X would automatically be funded in each institute on a yearly basis, this would in effect establish a degree of uniformity and reasonable stability for the extramural support programs. While variations may occur on a year to year basis, some degree

of predictability could be established. Although this approach has a strong appeal on the basis of emphasizing the research opportunities and investigator competency aspects, it has some innate drawbacks for the following reasons:

- a.) The budgeting for extramural support would of necessity be on a prospective basis and would thus be subject to surpluses or deficits. Contingency funds would of necessity have to be provided if this approach were to be implemented.
- b.) It places significant, and perhaps overwhelming, pressure upon the peer review process to maintain the objectivity necessary to make the system work, particularly for grants whose priority scores fall in the cutoff range.
- c.) It does not address the problem of intramural or contract support, demonstration centers, clinical testing or a host of other budgetary items where stability is also desirable.
- d.) It establishes an arbitrary limit which may be inappropriate either now or at some future time.

2. The Economic Indices Approach:

The level of support for biomedical research could be established as some fixed percentage of the total yearly health care expenditure based upon the total costs of health care for the period two years prior to the appropriation. Even more appropriate would be a decision to establish the biomedical research budget as a fixed percentage of the aggregate costs (direct costs plus indirect costs or losses due to morbidity, unemployability due to illness or mortality). By relating the research budget to the total economic burden of health care, there would be created a very substantial level of stability and a research budget which reflects the inflationary or recessionary state of the economy most closely. It is conceivable that the R & D deflator may be somewhat different than the comparable cost-of-health-care indices so that periodic readjustments in the fixed percentages would be necessary. It is envisioned that the fixed percentage budget would be a floor, but not necessarily a ceiling for the research budget which could then be increased by special congressional mandates. A suggested minimal figure would be between 1% and 1.5% of the aggregate costs.

3. The Baseline Approach:

A third mechanism would be to establish a baseline year at which optimal funding would be established. To this baseline figure each year would be added an amount of money necessary to compensate for the inflationary or recessionary trends since the baseline year. The great disadvantage to this approach is that it establishes some arbitrary figure which may not reflect the true costs of illness so that if the costs of illness increase disproportionately the percentage of expenditure of each health care dollar committed to biomedical research will, of necessity, erode or vice versa.

B. Response to Public Pressure

It is obvious that the congress is continuously being subjected to public sector pressures to increase support for certain categorical diseases. It is difficult to know how important these diseases are from the standpoint of the burden to society. For instance, a very aggressive vocal minority may exert so much pressure that funding is increased disproportionate to the true importance of that disease in terms of the constellation of disease entities, but one index of the importance of a disease is the amount of funds which can be raised by the various foundations to support research. Some consideration should be given to the possibility of the congress awarding matching funds for those privately solicited monies committed to biamedical research by the various philanthropic foundations or agencies. These funds would be contributed only to match those funds actually contributed to bona fide biomedical research and would be distributed to each institute or sub-unit of the National Institutes of Health and the Alcohol, Drug Abuse and Mental Health Administration as requested by the voluntary health agency or foundation in amounts proportionate to the funds contributed by the voluntary health agency or foundation to ensure that:

- (1) Only those funds contributed by voluntary health agencies or foundations for actual support of bona fide research are those to be matched and that
- (2) The voluntary health agencies and foundations are legitimate eleemosynary operations entitled to participate in the matching fund program and that
- (3) The distribution of the funds is consonant to the wishes of the participating voluntary health agencies and foundations, and to the mandate of the congress, '

A national bicmedical research funding panel should review all applications from voluntary health agencies and foundations for matching funds, and assign the funds to the appropriate institute or sub-unit. This approach would have a two-fold advantage:

- 1. It would serve as a stimulus to increase private philanthropic support for biomedical research
- 2. It would reduce the public pressures upon the congress for categorical disease support.

C. Scientific Opportunity

Some mechanism should be created to assure that greater flexibility in allocation of funds for scientific opportunity is provided. To accomplish this it is proposed that at least 10% of the total funds appropriated yearly for support of biomedical and behavioral research be non-targeted to any specific institute or any specific organizational

sub-unit. These contingency funds should be placed at the disposal of a national biomedical research funding panel to distribute among the various institutes or units of the NIH and ADAMHA for the following purposes:

- 1. To support promising new scientific opportunities where institute funds are limited
- 2. To stimulate new research in specific areas where great need is apparent for improved understanding of disease processes, enhanced technology, clinical testing or scientific evaluation, and which have not received congressional mandates or appear to be inadequately supported
- 3. To stimulate the overall development of scientific manpower with particular emphasis on programatic areas of high need
- 4. To promote dissemination of new information to health professionals
- 5. To promote programs of public information geared to preventive aspects of health care and early recognition of disease
- 6. To promote programs of immunization and screening for early detection of disease

The composition of the national biomedical research funding panel should be broad based and should include:

- 1. Two representatives from the Department of Health Education and Welfare appointed by the secretary
- 2. Three representatives from voluntary health agencies or foundations
- 3. Three representatives from the academic research community not employed by the federal government
- 4. Two representatives from the public at large
- 5. The director of the National Institutes of Health
- 6. The director of the Alcohol, Drug Abuse and Mental Health Administration.



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Office of the President: Theodore J. Phillips, M.D. Family Medicine Research Section — Room 200 U-District Building, University of Washington Seattle, Washington 98195, (206) 543-2461

August 9, 1978

Joseph A. Califano, Jr. Secretary of Health, Education and Welfare Washington, D.C. 20201

Dear Mr. Califano:

It is a pleasure to respond to your memorandum of July 19 concerning the HEW multi-year strategy for support for health research. That memorandum and the attached text of your remarks before the annual meeting of the American Federation for Clinical Research have been reviewed by three members of our Board of Directors and is in the process of being reviewed by others. In an attempt to comply with your timetable, I am responding now and will send additional information as others of our members reply to me.

First, I should identify the Society of Teachers of Family Medicine as being comprised of 1400 members all involved in family medicine educational and training programs. It is an interdisciplinary society with members representing medicine, social work, education, pharmacy, nursing, the behavioral and social sciences, etc. Our members work and carry on their professional activities in medical schools, community hospital teaching programs, and in a great variety of community based teaching practices.

The development of principles for a multi-year strategy is a laudable undertaking. We are pleased to see this happening and offer our support and assistance in whatever way is possible. To begin that process, I would list the following comments concerning those principles:

- 1. Your paper emphasizes the need for a balanced approach supporting basic research, applied research, and technology transfer. We would support that and urge that such a balance be maintained.
- 2. It is gratifying to see you refer repeatedly to the behavioral and social aspects of health research. When we use the term "basic research" we often think of research in the traditional biomedical sciences (anatomy, physiology, chemistry, etc.). Certainly many of the current benefits we enjoy in health care are due to such basic biomedical research. However, we are talking about health care of human beings who are also social beings. Basic research in the area of behavioral and social sciences is equally in portant to health care.

- 3. Your emphasis on the "population based" life sciences is gratifying. Perhaps this is merely an extension of point two above. I would like, however, to emphasize that an epidemiologic understanding of the occurrence of health and disease in populations must be basic to any health research effort.
- 4. The strategies adopted for health research support must certainly be oriented toward improving the quality of our nation's health and effectiveness of our health services. Questions of cost effectiveness and cost-benefit ratios are extremely important. One area deserving considerable emphasis is the development of appropriate measures of health. Health as a concept touches upon so many facets of an individual's life, it becomes an extremely complex item to measure. Whatever health research strategy is adopted should take this into account and enhance the development of appropriately broad measures of health status.
- 5. Finally, as might be expected given the nature of our membership, the Society of Teachers of Family Medicine strongly endorses the principle of interdisciplinary efforts in health research. Particularly do we support collaborative efforts between those working in medical schools and schools of public health, or departments of social and community medicine. In fact, current efforts to train future researchers in family medicine lean very heavily on cross-fertilization between clinical family practice and the population-based medical disciplines found within our schools of public health.

Thank you again for allowing us this opportunity to comment. We would be happy to give additional input as this effort proceeds. We hope you will continue to involve us in that process.

Sincerely yours,

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Theodore J. Phillips, M.D. President

TJP/gm

cc: Board of Directors
Society of Teachers of Family Medicine

Dr. Thomas Morgan Association of American Medical Colleges August 1, 1978

The Honorable Joseph A. Califano, Jr. Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

I am replying to your memorandum of July 19 asking for comments on the multiyear strategy for support of health research. We appreciate your invitation to make suggestions.

I strongly support the kinds of principles that you articulated in your Remarks before the American Federation for Clinical Research. There are a few notions that I would suggest:

- 1) Because health is a bio-psycho-social phenomenon it is essential to maintain fundamental research support in all of these areas. This includes socio-cultural, economic, and psychological aspects of health (both physical health and mental health) as well as the biological aspects that have been more traditionally considered to be research issues.
- 2) A substantial commitment of basic health research must go to improving health rather than to curing illness. This is much the same as the fourth principle in your Remarks.
- 3) Socio-epidemiological research regarding both health and illness must be included in the concept of basic health research. Many of our industrial toxins, contagious diseases, etc. have been detected and controlled through these approaches as well as through biomedical research.
- 4) The nation's health research commitment must include a commitment to the study of disability and dying as well as health and cure. There are many persons who will be disabled either permanently or temporarily and, of course, we must all die individually despite whatever health advances we can achieve as a nation. There must be research of disability, rehabilitation, and supportant cusabled and dying as part of the health commitment.

- 5) A substantial commitment of health research must be devoted to research regarding the programs to best deliver preventive, curative and restorative health care. This includes many aspects of manpower, economics, facilities, technology, organization of services. This area of health services research is not in the traditional spectrum of "basic" research, but it is fundamental even if not "basic" by certain scientific definitions. This is comparable to your fifth principle.
- 6) Research priority should be given to those areas that promise greatest health improvements for the most people such as nutrition, aging, child development rather than to narrow disease entities.
- 7) There should be mechanisms for not only assuring that all health research is multidisciplinary, but also that the various kinds of research are integrated with each other in the considerations of service planning. Too often basic biomedical research has been isolated from socio-epidemiological research or clinical research, and they in turn have been isolated from services research. We need them all in a coordinated pattern.

I would also agree that there is need to look at how the research functions are organized and deployed within the Department, but I'm not sure I feel that I have a principle to contribute here. I'm concerned, for example, that there is little focus on services research in the Alcohol, Drug Abuse and Mental Health Administration comparable to that of the National Center for Health Services Research.

I hope these ideas will be of some help.

Cordially yours,

Harold L. McPheeters, M.D. Director, Commission on Mental

Health and Human Services

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HLM/pc

cc: Mr. Stephen N. Collier

State Mental Health Research Directors

A Division of the National Association of State Mental Health Program Directors

August 15, 1978

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SMHRD

Donald Frederickson, M.D. Director National Institute of Health

9000 Rockville Pike Building #1, Room 124

Bethesda, MD 20014

Dear Dr. Frederickson:

The State Mental Health Research Directors Division of the National Association of State Mental Health Program Directors are responding to Secretary Califano's request for input on the DHEW Multi-Year Strategy for Support of Health Research.

We are highly supportive of both the need for such a strategy and Secretary Califano's viewpoint that its development will enhance the research effort. We strongly support the fourth and fifth principles articulated by the Secretary in his April 29, 1978 address.

In particular, we feel that the high priority support for basic research in biology and behavior should be balanced by an equally strong commitment to applied research; i.e., investigations of the quality, efficiency and effectiveness of health services and their delivery system. There should be a coordinated effort between federal and state authorities in identifying the priorities for applied health research.

There should also be a strong commitment to developing and implementing methods of technology transfer. Without attention to such methods, research results can only slowly, if at all, infuse the public sector.



Donald Frederickson, M.D. August 15, 1978 Page 2

We believe that federal commitments to expand applied research and technology transfer, working with state mental health authorities, can lead to substantial gains in the quality of mental health care and our ability to resolve many chronic and unresolved mental health problems.

Sincerely,

Barry Miller, Ph.D.

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Chairperson

cc: Gerald L. Klerman, M.D.
William Pollin, M.D.
Frank Sullivan, Ph.D.
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(415) 666-4544

August 21, 1978

Donald Frederickson, M.D. Director National Institutes of Health Room 124 NIH #1 9000 Rockville Pike Bethesda, MD 20014

Dear Dr. Frederickson:

A draft of the NIH Research Planning Principles has been called to my attention. I understand that you have scheduled a meeting in Washington on October 3 and 4 to invite comments on the principles from spokesmen for various health research interests, and that Dr. Doris Bloch will represent the Division of Nursing in those discussions. I would like to register my response, as well.

The draft NIH health research planning principles address the importance of a continued, but enlarged, base of support for health related research, that also can accommodate clinical trials and consensus activities. We would like particularly to endorse principle #4 regarding institutionally based resources, as more of the health science schools other than medical schools are increasing their research activities. Nursing's research activity is moving rapidly into the clinical science and bioethical arenas and into the fundamental behavioral sciences for explanations of human responses in health and illness.

I speak from the vantage point of a distinguished academic institution committed to graduate education and research, with unlimited possibilities for health care research but increasingly limited resources. Representing one component of that institution, the School of Nursing, we find ourselves more ready and capable of a substantial program of research than ever before, in terms of some resources, but limited in others. Diversified federal research funding strategies that include knowledge of the capabilities of all the health professional schools and of the contributions that behavioral, bioethical, and care-related (nursing) research can make to the quality of the entire health research enterprise would be welcome.

(continued)

Donald Frederickson, M.D. August 21, 1978 Page Two

I look forward to reports on the modification, adoption, and implementation of the principles.

Thank you.

Sincerely yours,

Margretta M Styles

Th Sp

Margretta M. Styles Professor and Dean

MMS:pf



T.S.A.A.

tuberous sclerosis association of america, inc.

†**9**lephone (617) 878-5528

August 15, 1978

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Joseph A. Califano, Jr., The Secretary Dept. of Health, Education & Welfare 330 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Califano:

I have read your memorandum to Professional Societies and Health Organizations dated July 19, 1978. In addition, I have studied the remarks you have made to the Annual Meeting of the American Federation for Clinical Research, April 29, 1978.

This Association is very supportive of your multiyear strategy for basic health research. We concur with your thought that, ... "our research dollars may go to popular causes, to the disease of the month, rather than to scientifically important endeavors." The health research plan you have outlined appears to be a well-considered concept and more equitable to the entire spectrum "of illness in America -- including mortality, disability, and cost."

Tuberous Sclerosis (TS) is a genetically transmitted autosomal dominant disorder. It is our understanding that the autosomal recessive disorders have been given more attention in the past because they are often caused by an enzyme defect and easier to approach. We would like to encourage research directed to the autosomal dominant disorders, including Tuberous Sclerosis. There are several hundred of these disorders, and current technology would allow for a more direct study of the nuclear mechanisms of TS and other autosomal dominant disorders of the nervous system than has been heretofore possible.

We would like to submit the following information for your immediate consideration:

Tuberous Sclerosis has many physical manifestations. Without question the two most prominent are (1) epilepsy (approximately 90% of known TS cases have a history of seizure problems ranging from mild to extremely severe); and (2) mental retardation (2/3rds or more of known TS patients suffer from mental retardation ranging from mild to extremely profound)

3-291

NATIONAL HEADQUARTERS

P.O. BOX 44 • ROCKLAND, MA. 02370

tuberous sclerosis association of america, inc.

Joseph A. Califano, Jr., The Secretary Dept. of Health, Education & Welfare Page Two August 15, 1978

Characteristic white macules (spots) are present in a very high percentage of TS cases. In fair skinned and newborn persons these spots may not be visible to the naked eye. A simple and readily available test for TS exists consisting of examining the individual with a Woods Lamp. (Under the lamp, these depigmented spots become visible.) This test is painless and does absolutely no harm to the subject and can identify 70%--90% of TS victims from birth onward.

TSAA feels that this test should be done in all newborn nurseries. Earliest identification of TS victims means earliest developmental intervention, as well as timely genetic counseling to parents of child bearing age. Thus improving the quality of care for those afflicted with TS, as well as reducing the rate of incidence.

Further, whenever possible, in cases of mental retardation and/or epilepsy (where the cause of the problem is not known) this examination should be given as a matter of routine procedure to be certain that TS may not be the basis of the problem(s).

At the recent NINCDS Forum, May 11-12, 1978, Dulles Airport, Marriott Hotel, Chantilly, Virginia, TSAA gave testimony before three panels:

1. Panel on Neurological Disorders--Developmental;

2. Panel on Convulsive and Neuromuscular Disorders; and

3. Panel on Neurological Aspects of Behavior.

In our testimony (copy enclosed, page five), TSAA has pointed out this very effective, easily instituted test to identify TS patients. Dr. Ferrendelli (Chairperson, Convulsive and Neuromuscular Disorders' Panel) and others seemed to feel this was of great significance and felt that the Woods Lamp test should be implemented on a national level.

TSAA would like the support of your office in pursuing federal implementation of this test. To date, properly utilized, it is the best tool available to detect and, through genetic counseling, prevent Tuberous Sclerosis. TS is such a potentially devastating disease, we feel that while we are waiting for medical science and research to unravel this genetic enigma, "an ounce of prevention is worth a pound of cure"

We thank you for your consideration and look forward to a prompt reply.

Since aly yours,

Rayword A. Connors, President

Tuberous Sclerosis Assn. of America

cc: TSAA Board of Directors

TSAA Medical Advisory Board 3-292

Tourette Syndrome Association.

August 3, 1978

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Melvin Yahr, M.D. Prof. and Chairman, Dept. of Neurology Mt. Sinai School of Medicine Joseph A. Califano, Jr.
The Secretary of Health, Education, and Welfare Washington, D.C. 20201

Dear Secretary Califano:

Thank you for giving our association the opportunity to submit our views and suggestions concerning the HEW multi-year strategy for support of health research. We are pleased to learn that President Carter has decided to reprogram \$93 million more to basic research for the '79 NIH budget.

We applaud this concept of a multi-year plan which in itself will make more efficient use of available funds by enabling researchers to build on their own momentum and focus on problems of greater substance that may require long-term study.

We further support each of the principles you outline as the underpinnings of the plan:

- . nurturance and support of new, young researchers
- emphasis on basic biomedical research
- better systems of communication between researcher and clinician so that new knowledge can be rapidly utilized for treatment.

There are several areas we have a particular interest in:
. The development of safe and effective drugs that do not contain the hazards of haloperidol, the current treatment of choice for G.T.S. We believe the government must take responsibility for encouraging drug companies, through subsidies or other means, to develop drugs for the control of low-incidence disorders such as ours.

It is appalling to us learn from other organizations that even a patient-population of one million is considered unprofitable as a potential market, therefore, not an interesting target area for research by these companies.

It seems to us that anguish cannot be quantified and profit should not be a factor in the alleviation of suffering.

. We are vitally concerned with your astute observation about the serendipitous nature of new discoveries. We would like to underscore your proposal for the encouragement of young researchers by directing your attention to the use of national workshops as brain-storming sessions between small groups of experienced investigators and post-doctoral candidates. Exorbitant sums of money do not have to be spent to set in motion promising ideas set forth by these young researchers. At one time, a resident at The New York Hospital enlisted the aid of the emminent immunologist, Dr. Robert Good, in an immunological investigation of G.T.S. This project cost us \$1000. Unfortunately, the provocative results were never

followed up because our limited resources precluded the support of more extensive studies.

There should be provisions at NIH for granting seed money to young researchers in the pursuit of promising, though unproven, hypotheses.

- The Gilles de la Tourette Syndrome has been cited by many investigators as a model disease for the study of neuropsychiatric disorders and the biochemical basis of behavior. Unravelling its complexities, although it is a low-incidence disorder, will surely shed light on other more common and debilitating conditions. Indeed, spin-offs from research of this disease can facilitate the understanding of mental illness, genetic disorders, the immune system, and minimal brain dysfunction in children as well as movement disorders.
- We ask that current knowledge about all related neurological disorders be applied to G.T.S. We envision the inclusion of this condition in current studies of other movement disorders as well as the areas mentioned above.
- . We are concerned with the genetic aspects of disease. We would like to see studies involving the identification of carriers so that the number of babies born with tragic genetic defects can be reduced.
- . We would like to see greater emphasis on preventive medicine and the understanding of the effect of nutrition on brain functioning and health in general.
- . We would like to see 100% of the approved grant requests funded.

Enclosed is a copy of a report we presented at a conference in May sponsored by NINCDS. In this document we make specific suggestions that may be of interest to you, such as the establishment of a national brain bank, a central data bank, clinical research centers for movement disorders and more efficient systems for the continuing education of practicing physicians.

We wish you success in this important venture and if there is any other information we can provide, please let us know.

Sincerely yours,

Betti Teltscher

President-T.S.A., Inc.

cc: Dr. Sheldon Novick
Mrs. Erica Feinholtz
members of the board of directors
members of the medical advisory board

Solidarily Slouse

DETROIT, MICHIGAN 48214
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August 2, 1978

Mr. Joseph A. Califano, Jr. Secretary
Department of Health, Education and Welfare
Washington, D. C. 20201

Dear Joe:

1 read with interest your remarks delivered to the Annual Meeting of the American Federation for Clinical Research and strongly endorse plans to develop a strategy to guide future health research. I also am encouraged by your efforts to involve representatives of the public in the planning of biomedical research activities.

As stated in testimony before the Subcommittee on Health and Scientific Research of the Senate Committee on Labor and Public Welfare, the UAW believes biological and medical research is a critical and integral part of the total health care system. New knowledge is always the first step to improvement in medical techniques and the prevention of disease. I have enclosed a copy of our testimony, which summarizes the Union's perspectives and recommendations on this subject.

We, too, place great importance on the development of a strategy to guide biomedical research activities and look forward to receiving a copy of the biomedical research principles prior to their presentation.

Sincerely,

Douglas A. Fraser, President INTERNATIONAL UNION, UAW

DAF/gb Enclosure opeiu494



United States Conference OF CITY HEALTH OFFICERS

1620 EYE STREET, NORTHWARE WASHINGTON, D. C. 20006 TELEPHONE (202) 293-7300

July 27, 1978

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Assistant Executive Director:
DEBORAH E. LAMM

Joseph A. Califano Secretary of HEW Room 615F South Portal Building 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Califano:

Thank you for this opportunity to submit comments about the future of Federal support for health research. It is a most welcome change to contribute policy recommendations at a preliminary stage rather than attempt to make changes after policy has been formed.

The United States Conference of City Health Officers (USCCHO) as a group representing the health departments of local government relates in a unique way to health research. By and large, we do not engage in it. What we do as provide research data and utilize research findings.

It was with particular interest that I reviewed two of the five areas discussed in your April 29th presentation before the annual meeting of the American Federation for Clinical Research.

You noted that "our government-supported research ust have a strong orientation toward improving the quality of our nation's health and effectiveness of this nation's health services." Clearly, it is important that such an activity take place. One component of this effort should be directed toward the relationship between health services delivery and local health departments. should be taken to determine the amounts and means in which funds are being distributed, whether there is enough funding to effectively administer the programs which are receiving money for health services, who in local health departments is performing what services, how effectively health administrators and health providers are working together in this setting, what research needs are identified by local health departments, etc. At present, information about health departments' organization and structure is available only through state health departments. information is uneven and sketchy, at best.

Secretary Joseph A. Califano page two July 27, 1978

You stated too, "a fifth and final principle is that HEW-supported research must be more effectively oriented to develop knowledge bases that support not just some but all the health missions of the Department--prevention, delivery, regulation, standard setting, and cost control." We at the local level of health services delivery strongly endorse such a goal. Again, in order to measure results, one must be able to analyze the factors which contribute to the success or failure of the results. We must know more about local health departments.

Thank you for writing to me about this important subject. Please let me know if we can be of assistance to you.

Very truly yours,

John J. Gunther
Executive Director

cc: Donald Fredrickson, M.D.

ANDREW PATTULLO
Vice President — Programs

W.K.KELLOGG FOUNDATION

August 8, 1978

The Honorable Joseph A. Califano, Jr. The Secretary of Health, Education, and Welfare .
Washington, D.C. 20201

Dear Mr. Califano:

Dr. Mawby has asked that I respond to your letter of July 19 in which you invite our comments concerning the issue of Federal support for health research.

The W. K. Kellogg Foundation is not an organization that provides support for research activities. Rather, our historic and continuing concern has been directed toward the application of research findings. For that reason we would not have any specific comments to make in regard to the development of proposed principles relating to Federal support for health research. However, we would observe that it is obvious that the Federal Government's extensive investment in health science research is of critical importance, both nationally and internationally. It is also, I believe, a matter of some public concern that the "payout" in terms of the results of this extensive research has been somewhat disappointing from the standpoint of the improved health status of the American people. Therefore, it would seem that your effort to develop a multi-year strategy to guide the allocation of these dollars is a very appropriate one in which to engage. We wish you all success in this direction.

Sincerely yours,

AP/ns



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August 25, 1978

The Honorable Joseph A. Califano, Jr. Secretary Department of Health, Education and Welfare Washington, D. C. 20201

Dear Mr. Califano:

I note with great interest your efforts to establish a multi-year strategy for support of basic research in medical sciences. It is refreshing to see this viewpoint expressed at a high level of government administration because I feel, as do many thoughtful biomedical scientists that the big payoff comes only with new knowledge and new principles developed in the laboratory by the bench scientist.

As a cancer researcher with many years of experience in laboratory research and editorial work, as well as participation in many national committees, I have been increasingly concerned that the cancer program in particular has been fragmented to the extent that the all important basic science effort has not received the important support that it deserves and needs if we are to see a solution.

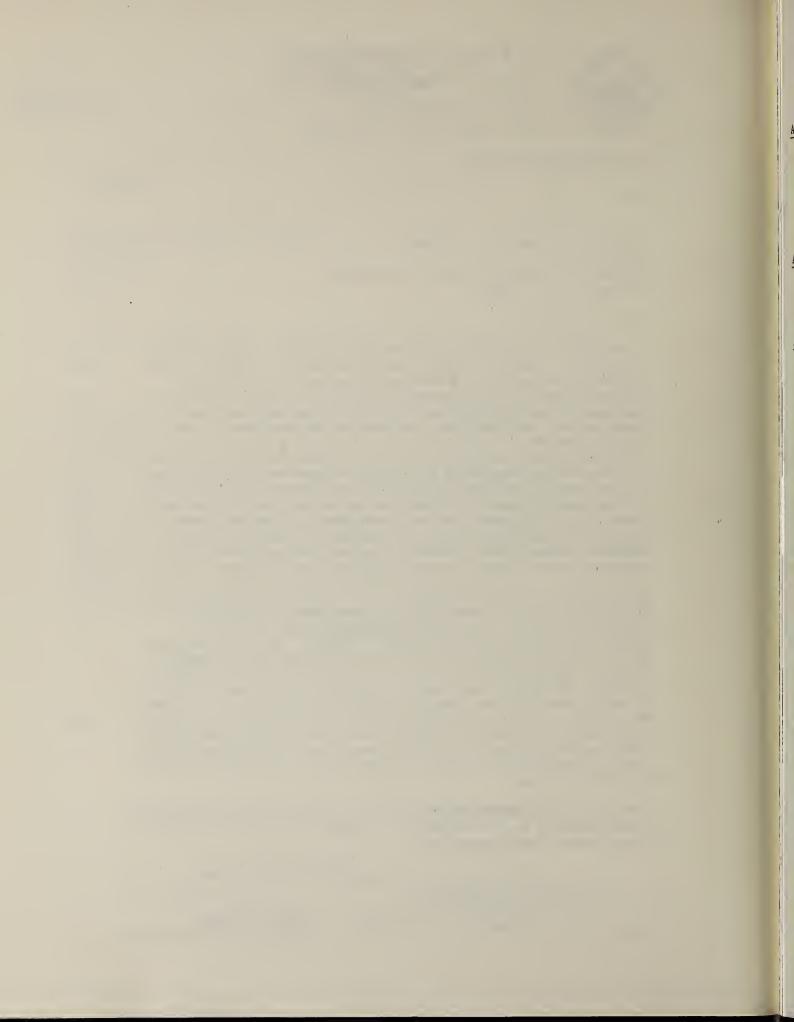
Another area which has been neglected is that of research training. It is difficult to overemphasize the importance of training in biomedical sciences in partnership with the research effort. There are two main reasons for this. Trainees, both pre- and postdoctoral, provide the competent, highly motivated and productive manpower (and womanpower) working in partnership with the researcher. Secondly, training is necessary to replenish the scientific pool. If one figures that the productive years of a scientist is at most 40 years, it would be necessary to replace 2.5% of scientists each year merely to maintain the present level of scientific effort. For these reasons, the modest financial requirements constitute one of the best investments the federal government can make toward progress in medical science.

I hope to follow the proceedings of the conference you are holding on October 13rd and 4th and emphasize my support of your efforts in the direction of a multi-year plan.

cc: Dr. Donald S. Frederickson Director, National Institutes B-299of Health jdb/

Sincerely yours

illity of Melleron Sidney Weinhouse Professor of Biochemistry



LISTING OF ATTACHMENTS

RECEIVED WITH LETTERS OF COMMENT

Alternatives to Abortion International

"Seventh Annual Alternatives to Abortion International Board Meeting," August 10-13, 1978, St. Louis, Missouri.

"Pro-Life Emergency Pregnancy Service Centers Worldwide Directory" (11th ed.), 1978.

American Brittle Bone Society, Inc.

Thomas, Lewis. The Lives of a Cell. Notes of a Biology Watcher. New York: Viking Press, pages 31-36.

American Colleges of Obstetricians and Gynecologists

"ACOG Statement of Policy. Maternal Health Policy," December 1977.

American Pharmaceutical Association

"Comments by the American Pharmaceutical Association to the President's Biomedical Research Panel." <u>Journal of Pharmaceutical Sciences</u>, 1975, pages 3-6.

Amyotrophic Lateral Sclerosis Society of America

- Bishop, H. Eames. "Statement by the Amyotrophic Lateral Sclerosis Society of America to the Public Forum Held May 11-12, 1978, for the Purpose of Input in Connection with the Long-range Planning of National Research Strategy for Neurological and Communicative Disorders." Chantilly, Virginia.
- Letter dated February 15, 1978, from Richard T. Johnson, M.D., The Johns Hopkins University School of Medicine, Baltimore, Maryland to H. Eames Bishop, ALS Society of America, Sherman Oaks, California.
- Discus, Robert G. "Hospital Based Home Care (HBHC) Programs for Amyotrophic Lateral Sclerosis (ALS) and Other Handicapped Patients and Families."
- "Information Fact Sheet. Aide/Attendant Programs."
- "Aide/Attendant Programming for ALS."
- "Information Fact Sheet. Supplemental Security Income (SSI)."

- "Information Fact Sheet. Homemaker and Chore Services."
- "California Association of the Physically Handicapped (CAPH)
 Wins New SSI Law." New World for the Physically Handicapped,
 December 1977.

Association for Children with Learning Disabilities

"Areas of Research Needed in Learning/Behavioral Disorders."

"The LD Child Grows Up." ACLD Newsbriefs, September/October 1978, page 5.

Association of American Medical Colleges

Carey, William D. "Patent Policy Versus Innovation." Science, June 30, 1978.

Bergstrom, Sune, M.D., Chairman, Advisory Committee on Medical Research, World Health Organization

"American Support of International Biomedical Research Programs: A Swedish Viewpoint." Advances in American Medicine.

The Commonwealth of Massachusetts, Department of Mental Health

"Summary of Research Regulations."

Dennehy, Raymond, Ph.D., University of San Francisco

"The Philosophy of Human Experimentation." The New Scholasticism, 1978, pages 81-90.

Down's Syndrome Congress

Glasgow, Robert E. "Testimony Presented to the U.S. Congress on the Proposed Budget for the Department of Health, Education and Welfare."

Institute of Food Technologists

Niven, C. F., Jr. "Nutrition, Diet and Disease: II -- Implementation of Dietary Improvements. Where Should We Go From Here in Improving the U.S. Diet?" Presented at the Institute of Food Technologists Annual Meeting, June 5, 1978. Dallas, Texas.

International Union, UAW

Woodcock, Leonard. "Testimony Presented to the U.S. Senate on Biomedical Research Policy," April 1, 1977.

Maternity Center Association

Lubic, Ruth Watson. "Maternity Center Association's Childbearing Center: Innovation and Controversy." Presented at the 105th Annual Meeting of the American Public Health Association, October 21, 1977. Washington, D.C.

National Black Nurses' Association

"Providing Health Care for Unserved and Underserved Ethnic Minority Communities," August 15, 1978.

"Birth Control Pills: Effect on Teenagers and Young Adults, Personality Changes and Labile Behavior."

National Paraplegia Foundation

Subcommittee, National Advisory Council of the National Institute of Neurological and Communicative Disorders and Stroke. "The Current Status of Research on Growth and Regeneration in the Central Nervous System." Surgical Neurology, March 1976, pages 157-160.

Racker, Dr. Efraim, Cornell University

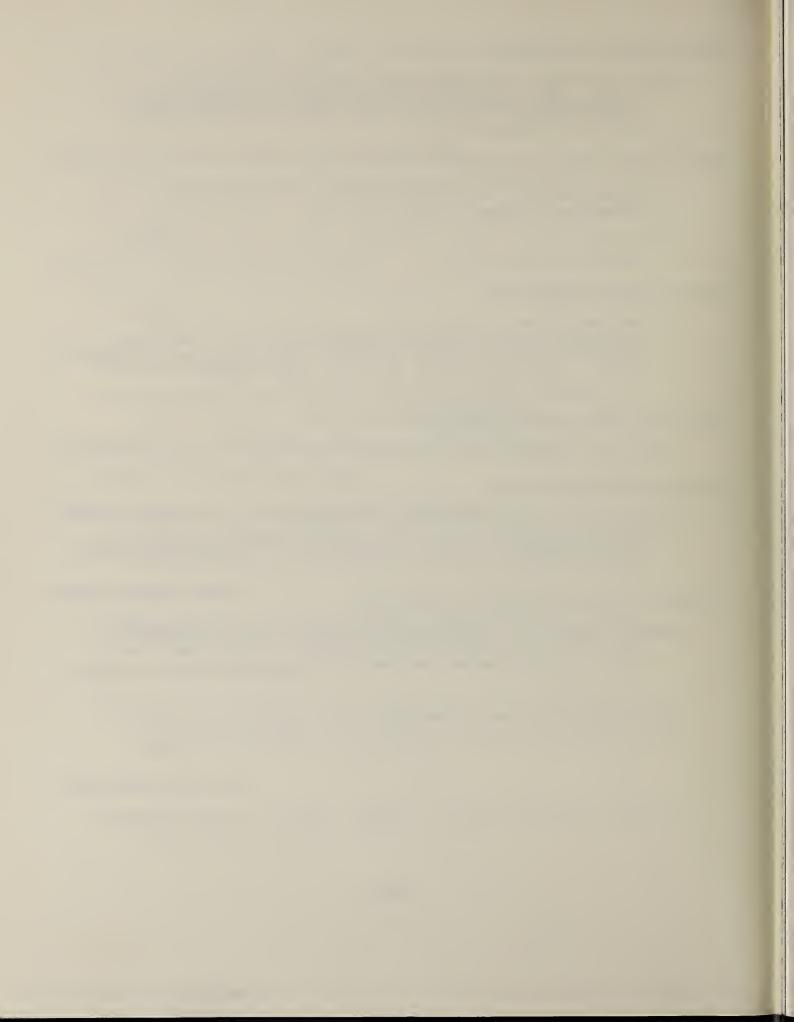
"Science for People"

Tourette Syndrome Association

Teltscher, Betti, and Novick, Elaine. "Presentation by the Tourette Syndrome Association to the Public Forum for the Development of a National Research Strategy for Neurological and Communicative Disorders," May 11-12, 1978.

Tuberous Sclerosis Association of America, Inc.

Connors, Raymond A. "Statement by the Sclerosis Association of America, Inc., to the Public Forum for the Development of a National Research Strategy for Neurological and Communicative Disorders."











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